8-2012

End-of-Life Culture Care Expressions, Meanings, Patterns, and Practices among Yup'ik Eskimo

Pamela J. Embler
College of Nursing and Allied Health Sciences, pembler@utk.edu

To the Graduate Council:

I am submitting herewith a dissertation written by Pamela J. Embler entitled "End-of-Life Culture Care Expressions, Meanings, Patterns, and Practices among Yup'ik Eskimo." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.

Mary Gunther, Major Professor

We have read this dissertation and recommend its acceptance:

Sandy Mixer, JoAnne Hall, Gregory Button

Accepted for the Council:
Dixie L. Thompson

Vice Provost and Dean of the Graduate School

(Original signatures are on file with official student records.)

End-of-Life Culture Care Expressions, Meanings, Patterns, and Practices among Yup'ik Eskimo

A Dissertation Presented for
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

Pamela J. Embler
August 2012

Acknowledgements

I gratefully acknowledge and express my sincere appreciation to my dissertation committee, Dr. Mary Gunther, Dr. JoAnne Hall, Dr. Sandra Mixer, and Dr. Gregory Button, for their contributions to this dissertation and my scholarly growth. To my husband and our children I acknowledge their support, encouragement, and sacrifice without them this work would not have been possible. To all of the doctoral students in my cohort, especially Tese Stephens, it has been a pleasure and an honor to travel this scholarly journey with you. Finally, I am especially grateful to the community of Bethel, the surrounding villages, my gatekeepers, and all of the informants who participated in this study and shared their stories with me.

Finally, I gratefully acknowledge the generous support of the Transcultural Nursing Society 2012 Research Award which provided partial assistance for the completion of this study.

Abstract

The need for end-of-life care research is exemplified by the fact that the National Institutes of Health has made this topic a research priority. End-of-life care is multifaceted and concepts become complex when cultural perspectives are considered. The purpose of this qualitative ethnonursing study was to discover culture care expressions, meanings, patterns, and practices at end-of-life among Yup'ik Eskimo in community settings. Data was obtained from Yup'ik Eskimo of the Yukon-Kuskokwim Delta, Alaska. The Culture Care Diversity and Universality Theory and the ethnonursing research method directed this study. Key and general informants were interviewed. Interviews and observations were analyzed. The following three themes supported by the recurrent care patterns and key and general informant descriptors are (a) care is *uptete* (to get ready to go), (b) care is *ilakellriit* (community and family), and (c) professional care is *to do*. Nurses providing end-of-life care to Yup'ik Eskimo need to know what is important, fulfilling, useful, and meaningful as described within a cultural context by the Yup'ik Eskimo in order to promote culturally congruent care. Findings of this study will be useful to the nurses and all other healthcare providers who care for Yup'ik Eskimo. This study further supports and substantiates the Theory of Culture Care Diversity and Universality and contributes to the body of transcultural nursing knowledge.

Keywords: end-of-life, Yup'ik Eskimo, The Theory of Culture Care Diversity and Universality, ethnonursing research method

Table of Contents

Chapter 1

Introduction

The National Institutes of Health (NIH)/National Institutes of Nursing Research (NINR) contend that there is not a precise definition of end-of-life; rather it can be identified by its attributes. End-of-life often involves a chronic illness, symptoms, or impaired functional ability which may be irreversible, require formal (professional care) or informal assistance (caregiver assistance), and result in death (NIH, 2004). The need for research related to end-of-life care is a NIH/NINR priority. Therefore, discoveries of end-of-life culture care expressions, meanings, patterns, and practices leading to improved culturally congruent end-of-life care support these recommendations. Since people from diverse cultures can experience end-of-life care differently, I propose the logical first step is discovery using Leininger's qualitative ethnonursing methodology. Ethnonursing (Leininger, 1990, 2006a) adds to ethnography by bringing an etic (outsider) nursing perspective to the emic (insider) view of known cultural lifeways. The goal of ethnonursing is the use of action/decision modes to utilize discovered lifeways which promote culturally congruent care; care that is meaningful and beneficial to its recipients.

Culture influences how we assign meaning to events, in this instance end-of-life. Cultural factors confound death in two ways (a) what is seen at the time of death, the absence of life and (b) what is believed at the time of death, the meaning of death and what happens after death. Culture defines how we grieve, how we mourn, and how we

are to remember the person who has died (Braun, Pietsch, & Blanchette, 2000; Seno, 2010; Quinn, Schmitt, Baggs, Norton, Dombeck, & Sellers, 2012). The dichotomy between what is seen and what is believed at the time of death is further influenced by medical, legal, and ethical factors which affect our experiences. Dying has been medicalized and as a result is often prolonged (Gates, 1988; Quinn et al., 2012; Teno, Clarridge, Casey, Welch, Wetle, Sheild, & Mor, 2004). This creates a false perception that dying can be planned, controlled, and precisely prognosticated (Braun et al., 2000; Teno et al., 2004). The two obvious shortcomings of medicalized dying and death are that: (a) death and dying have become invisible and unfamiliar to family members or significant others and (b) death and dying care practices have been delegated to professionals as dying has moved from the home into hospital settings (Hardwig, 2009).

Braun et al. (2000) note that end-of-life is incongruent with the medical model of healthcare in four major ways: (a) medicine, not culture, defines advanced age and death, (b) technology augments end-of-life care, (c) the patient, family, and healthcare professionals often have competing if not conflicting goals of care, and (d) few lay people are knowledgeable about the available life prolonging technologies and the implications which these technologies add to the decision-making process at end-of-life. Few healthcare providers are knowledgeable about the multiple complexities of culture (Braun et al., 2000; Hawryluck, 2004; LeBlanc, Wheeler, & Abernethy, 2010; Quinn et al., 2012; Seno, 2010). These complexities challenge the care that the nurse provides when unaware of patient preferences. A widening of the cultural lens allows for an

appreciation of others' view of the world. While we all live in the same world, we must be open to the reality that we all may see this world differently.

When we appreciate differences we begin to appreciate commonalities. This allows for cultural relativism. Culture care expressions, meanings, patterns, and practices are contextual. They are bound to the historical and environmental context in which they unfold (Braun et al., 2000; Leininger, 2006a, Seno, 2010). Braun et al. (2000) assert that healthcare professionals have a moral responsibility to (a) learn about the cultures of their patients, (b) recognize their own values, (c) accept that their own way is not the only true reality, and (d) develop the skills necessary to interact and communicate in a non-judgmental way in culturally diverse societies. Seno (2010) contends healthcare providers need to move beyond caring for the dying to unconditional *being with* and *attending to* the dying in end-of-life encounters. Broadening our lens leads to non-judgmental understanding and improves our ability to interact and communicate across cultures. This ultimately provides for improved end-of-life care.

Purpose

The purpose of this ethnonursing study was to discover the end-of-life culture care expressions, meanings, patterns, and practices among Yup'ik Eskimo of the Yukon-Kuskokwim Delta, Alaska. The goal of this study was to discover emic (generic/folk) and etic (professional nursing) care that promotes culturally congruent end-of-life care for Yup'ik Eskimo.

Significance

Discovery of Yup'ik Eskimo end-of-life culture care expressions, meanings, patterns, and practices leading to improved culturally congruent end-of-life care support the NIH/NINR research recommendations. End-of-life culture care is multifaceted and needs to be investigated to discover and understand complexities. I propose that culture care variations and intra-culture care variations complicate culturally congruent end-of-life care for patients, families, and communities. Culture and care cannot exist one at the exclusion of the other (Leininger, 2006a).

Persons at or near the end-of-life are an extremely vulnerable population. Hawryluck (2004) noted that persons at end-of-life are in need of advocacy. End-of-life care is an area of interest in resurgence (Hawryluck, 2004); however ethical tensions often constrain research efforts (LeBlanc et al., 2010). According to LeBlanc et al. (2010) care delivered at the end-of-life has been historically based on empathy, clinical decisions, and past experience. The focus in these instances is etic not emic with much of what is known subjective rather than research-based. This may be due to research goals being in direct opposition to goals of care. Where research goals are etic versus emic focused then outcomes are centered on the professional rather than person. Research among persons at end-of-life places unnecessary burdens upon the dying individual, their families, and the community (LeBlanc et al., 2010). Research designs need to be sensitive to patient and family end-of-life care needs while addressing the gaps in what is known and unknown about end-of-life care.

Dying and death were discovered to be a processes dependent on the meanings held by the individual, the family, or community within the context the culture (Baydala, Hampton, Kinunwa, Kinunwa, & Kinunwa, 2006; Bonura, Fender, Roesler, & Pacquiao, 2001; Gelfand, Balcazar, Parzuchowski, & Lenox, 2001; Kaufman & Morgan, 2005). Bonura et al. (2001) in their data-based study examined the culturally generic values, beliefs, and practices of end-of-life care for Jewish patients. The purpose of this ethnonursing study was to determine how culturally held values, beliefs, and practices of Jewish persons influenced end-of-life care decision-making. Seven culturally relevant themes which were indicative of cultural and religious obligations emerged from the interviews (Bonura et al., 2001).

Gelfand, Balcazar, Parzuchowski and Lenox's (2001) data-based study examined end-of-life care attitudes among minimally acculturated Mexican-Americans and Mexicans residing in Michigan and Arizona. Three main perspectives of hospice care were generated from the focus groups: (a) the role of the family, (b) the role of hospice, and (c) the role of the church. Findings indicated that the family was viewed as the provider of end-of-life care; therefore, relying on hospice was viewed as an embarrassment or an inability to care for one's own family member. For family members, hospice was not needed to provide for affective needs; hospice was viewed as necessary only for professional nursing care needs (i.e., bathing, dispensing medication, or treatment regimens). The role of the church was important in meeting the spiritual and emotional needs related to end-of-life care. Participants were not able

to offer any suggestions on how hospice might assist in meeting spiritual or emotional needs.

Cultural factors add multiple layers and complexities to what is known about end-of-life care. Culturally diverse patient populations challenge health care providers to promote more than culturally sensitive care. Care must be culturally congruent. While specific examples of varying cultural end-of-life care expressions, meanings, patterns, and practices are recorded, I located little research which examined the perspective among Yup'ik Eskimo exclusively.

In their qualitative personal narrative Baydala et al. (2006) explore First Nation Aboriginal perspectives of end-of-life and dying from the stories shared by two persons. Researchers cautioned that the narratives were not intended to predict meaning, provide definitive conceptualizations, or infer generalizability among all First Nations Aboriginals. The resultant dialogue was offered to bridge Western medicine and Aboriginal beliefs and care meanings. Baydala et al. (2006) stated that whatever the course of dying and death ("quick, foreseen, violent, peaceful, alone, or together" p.163) respectful understanding creates the foundation for how we care for self and others.

Kaufman and Morgan's (2005) essay highlights the movement of anthropological examinations of birth, life, and death from "descriptions of normative" (p. 318) to a reflexive analysis of the biopolitical factors, i.e. culture of medicine, which influence the social context of birth and dying. Most recently DeCourtney, Branch, and Morgan

(2010) conducted focus groups in six different locations of remote and urban Alaska. The result of this work was compiled into a just-in-time palliative care handbook for caregivers. Needed now is a reference for caregiving professionals in hospital settings when dying at home is not possible.

The end-of-life culture care needs of the Yup'ik Eskimo are not known. Nurses providing end-of-life care to Yup'ik Eskimo need to know what is important, fulfilling, useful, and meaningful as described within a cultural context by the Yup'ik Eskimo in order to promote culturally congruent care. Findings of this study are useful to nurses who care for the Yup'ik Eskimo by contributing to both the body of transcultural nursing knowledge and end-of-life care knowledge.

Domain of Inquiry and Research Questions

The domain of inquiry defined by Leininger (2006a) allows for purposeful guided inquiry into cultural lifeways and unknown health patterns and practices. The domain of inquiry for this study is the culture care expressions, meanings, patterns, and practices related to end-of-life care among Yup'ik Eskimo.

Four research questions guided my inquiry and served to generate new knowledge and address the limited information regarding Yup'ik Eskimo end-of-life culture care.

1. What are the culture care expressions, meanings, patterns, and practices related to end-of-life care among Yup'ik Eskimo?

2. In what ways do worldview and cultural and social structure factors, (i.e. religion [spiritual] & philosophical; kinship & social, political & legal, education, economics, technology, cultural values, beliefs and lifeways, ethnohistorical, and environmental) influence end-of-life culture care expressions, meanings, patterns, and practices for Yup'ik Eskimo?
3. In what ways does generic and professional care assist with or inhibit the end-of-life culture care expressions, meanings, patterns, and practices for Yup'ik Eskimo?
4. Based upon the discovery of Yup'ik Eskimo end-of-life care, what nursing action/decision modes promote culturally congruent end-of life care expressions, meanings, patterns, and practices for Yup'ik Eskimo?

Philosophical Orientation and Theoretical Framework

This study is situated within the post-positivist, naturalistic, and participatory worldview paradigms. End-of-life culture care is posited to be full of complexities which cannot be understood by the adoption of one empirical truth. The best chance for meaningful discovery is through a lens of multiple truths; by appreciating end-of-life care as it is understood and described by the persons whose experiences are in everyday living and with the participation of the cultural community of interest.

A cookie cutter approach to death and dying is not possible in a multicultural society. We are a pluralistic society (Locke, 1992). In a pluralistic society "members of diverse ethnic, racial, religious, or social groups maintain an autonomous participation in and development of their traditional culture or special interest within the confines of a common civilization" (Pluralistic, n.d.). Furthermore, adoption of a pluralistic society embraces the existence of multiple realities. A pluralistic view allows for an appreciation of more than one truth about death and dying.

The Culture Care Theory (CCT) framework directed this study. Recognizing multiple truths inherent in multiple cultures in a society requires more than tolerance of existence. For nurses this means that we must be cognizant of end-of-life care differences and similarities. Leininger (2006a) embraces death as part of life. The CCT uses discovery to understand relationships of culture care and health phenomena. In order to promote culturally congruent end-of-life care, "authentic truths" (p. 21) as described by the knowers of care (Yup'ik Eskimo) potentiate the discovery of end-of-life "care and cultural phenomena within their world" (p. 21). The philosophical orientation for this study is congruent with CCT and directs the domain of inquiry.

The central concepts of the theory are care, culture, and culture care. Leininger (2006a) proposed the concepts culture and care as markedly absent from the metaparadigm of nursing. Care, according to Leininger (2002) is embedded in culture; therefore, culture care is necessary to promote health and facilitate meaningful nurse/patient interactions (Leininger, 2006a). Leininger posited that nurses would be

challenged to care for persons from diverse groups within society. The distinctiveness of ethnonursing is its attention to demonstrate culture care diversity and universality inherent within and among cultures, in this instance the Yup'ik Eskimo culture and the nursing culture. Research conducted within the CCT advances nursing knowledge about diverse and similar groups. The ethnonursing research method uses open discovery which promotes culturally congruent care.

Assumptions

The following theoretical assumptions are derived from the assumptive premises of the CCT and guide the research discovery of culture care expressions, meanings, patterns, and practices related to end-of-life care among Yup'ik Eskimo.

1. Care is essential to Yup'ik Eskimo at end-of-life (adapted from Leininger assumption number 1, 2006a, p. 18).
2. Culture care expressions, meanings, patterns, and practices for Yup'ik Eskimo are influenced by and embedded in worldview and cultural and social structure factors, (i.e. religion [spiritual] & philosophical; kinship & social, political & legal, education, economics, technology, cultural values, beliefs and lifeways, ethnohistorical, and environmental) (adapted from Leininger assumption number 6, 2006a, p. 19).
3. Every culture has generic (lay, folk, naturalistic; mainly *emic*) and usually some professional (*etic*) end-of-life care to be discovered

and used for culturally congruent practices (adapted from Leininger assumption number 7, 2006a, p. 19).

4. Leininger's three theoretical modes of care offer new, creative, and different therapeutic ways to help Yup'ik Eskimo with end-of-life care (adapted from Leininger assumption number 9, 2006a, p. 19).

Orientational Definitions

Orientational definitions regarding end-of-life care are congruent with the NIH/NINR State of the Science Conference Statement on Improving End-of-Life Care (2004) and the Culture Care Diversity and Universality Theory (Leininger, 2006a). Leininger (2006a) holds that there is cultural diversity inherent in words. Orientational definitions as opposed to operational definitions maintain fluidity and allow the researcher to discover culture care meanings. The purpose of orientational definitions is to maintain a qualitative participant focus not a researcher focus. In this way research is consensually directed which potentiates replication and further knowledge advancement of end-of-life culture care.

End-of-Life

There is no definitive or generally agreed upon definition of end-of-life in the literature. The NIH/NINR (2004) proposes a definition based on attributes to include chronic illness, symptoms, or impaired functional ability which are often irreversible,

require formal assistance (professional care), informal assistance (caregiver assistance), and results in death.

For this study, end-of-life is defined broadly to include a sudden event; the result of a trauma or immediate pathophysiological event, and the time which includes an illness or disease that precipitates death. Regardless of the brevity or the chronicity involved, end-of-life is a process.

Culture

Culture is what is learned, shared, and handed down among a specific group of people. Values, beliefs, norms, and lifeways of a culture influence thinking, decisions, and actions in predictable ways (adapted from Leininger, 2006a, p. 12). In this study culture of the Yup'ik Eskimo is specific to the Yup'ik Eskimo of the Yukon-Kuskokwim Delta region of Alaska.

Care

Leininger defines care as actions or attitudes which serve to improve lifeways and holds that care is embedded in culture. Care can be expressed as protection, as respect, or as physical or emotional presence (adapted from Leininger, 2006a, p. 12). Yup'ik Eskimo care (a) refers to the abstract or concrete phenomena which go beyond doing and (b) incorporates cultural meanings.

Culture Care

Culture care is more than the symbols or rituals inherent to a people. Culture care is the transmitted knowledge of expressions, meanings, patterns, and practices that assist, support, facilitate, or enable individuals or groups to sustain well being, improve or maintain health, or to experience end-of-life (adapted from Leininger, 2006a, p. 13).

Culturally Congruent Care

Leininger defined culturally congruent care as culturally rooted care. Actions and decisions are epistemologically and ontologically based upon previously discovered cultural lifeways. Culturally congruent care is meaningful and appropriate care of clients that supports health and wellbeing; prevents illness; and supports disabilities or death (adapted from Leininger, 2006a, p. 13).

Lifeways

Lifeways are the culturally situated expressions, meanings, patterns, and practices which are useful in explaining health, non-health, and end-of-life care needs of individuals and groups. The discovery of lifeways allows for an appreciation of the universalities and diversities among cultures. Emic and etic perspectives are used to identify similarities and differences which guide action and decision modes of end-of-life care (adapted from Leininger, 2006a, p. 12).

Emic

Folk or generic learned and shared knowledge of lifeways are the cultural situated values, beliefs, meanings, and practices which explain health, non-health, and predict illness of individuals and groups (adapted from Leininger, 2006a, 13). In this study the Yup'ik Eskimo end-of-life culture care views are the emic views.

Etic

Professional knowledge is formalized from cognitively and affectively learned knowledge from established educational institutions. Etic views are the outsider views (adapted from Leininger, 2006a, 13). In this study all non-Yup'ik Eskimo views (i.e., nurses, physicians, clergy, law enforcement officials) are considered the outsider views.

Action and Decision Modes

Leininger (2006a) proposed three action and decision modes of nursing care which support culturally congruent care: (a) culture care preservation/maintenance, (b) culture care accommodation/negotiation, and (c) culture care repatterning/restructuring. Culture care preservation and maintenance assist, support, facilitate, or enable action or decisions that help nurses preserve or maintain beneficial end-of-life expressions, meanings, patterns, and practices for Yup'ik Eskimo (adapted from Leininger, 2006a, p.8). Culture care accommodation and/or negotiation assist, support, facilitate, or enable nurse actions and decisions that help to negotiate or

accommodate Yup'ik Eskimo culturally congruent expressions, meanings, patterns, and practices during end-of-life care (adapted from Leininger, 2006a, p.8). Culture care repatterning and/or restructuring assist, support, facilitate, or enable nurse and Yup'ik Eskimo to mutually reorder, change, or modify end-of-life care (adapted from Leininger, 2006a, p.8).

Environment

Leininger (2006a) holds that the environment is a major construct of the CTT. The environment goes beyond the geophysical and ecological setting. The environment influences the end-of-life care since the environment is the basis of the expressions, meanings, patterns, and practices of the shared views and values of Yup'ik Eskimo end-of-life culture care. Discovery of the environmental context related to the end-of-life care expression, meanings, patterns, and practices for Yup'ik Eskimo will promote culturally congruent end-of-life care.

Limitations

Linguistic limitations are acknowledged. In translation, Yup'ik Eskimo to English or English to Yup'ik Eskimo, words may not exist to fully describe the expressions, meanings, patterns, and practices of end-of-life culture care for Yup'ik Eskimo. Similarities among or between Yup'ik Eskimo or other Alaska Natives peoples are anticipated; however, an assumption of transferability could potentiate bias and stereotyping. Discovery and study findings of the end-of-life care expressions, meanings, patterns, and practices among the Yup'ik Eskimo findings are limited to the

naturalistic community setting. Discovery did not occur while in crisis, trauma, or in hospital contexts.

Chapter Summary

The diverse culture care needs of patients and the provision of culturally congruent care at the end-of-life often puts nurses in a difficult position as the emic view of health care and health practices of the patient might clash with the etic view of Western medicine**.** The end-of-life culture care needs of the Yup'ik Eskimo are not known. Nurses providing end-of-life care to Yup'ik Eskimo need to know what is important, fulfilling, useful, and meaningful as it is described within a cultural context by the Yup'ik Eskimo in order to promote culturally congruent care. Applying general portrayals of dominant cultural or ethnic group practices is not acceptable and potentiates stereotyping and bias. To promote culturally congruent care it is important that Yup'ik Eskimo end-of-life culture care needs be explored in an effort to discover and share knowledge within the profession of nursing.

Chapter 2

Review of Literature

The purpose and goal of this ethnonursing study was to discover the end-of-life culture care expressions, meanings, patterns, and practices among Yup'ik Eskimo in order to promote culturally congruent end-of-life care for Yup'ik Eskimo. I approached the review of literature from the emic (generic/folk) and etic (professional) perspectives. The following discussion from the literature addresses the Yup'ik Eskimo ethnohistory to include the worldview, kinship and social factors, and cultural values beliefs and lifeways. A review of the end-of-life literature is provided which examines death and dying in the health care system from both the patient and health care provider perspectives. Culture care experiences at end-of-life literature focuses on family, gender, religiosity/spirituality, and decision making. Discussion about cultural barriers to end-of-life care includes communication, language, distrust, and geographical factors. Contextual experiences at end-of-life may occur in hospitals, hospice or at home and may involve ethical and professional dilemmas. Finally, the need for further research is identified.

Yup'ik Eskimo

The environmental context of this study was the Yukon-Kuskokwim Delta (Y-K Delta) region of Alaska and the cultural group of people who inhabit this region. This triangular region of southwest Alaska is formed by the two largest rivers in Alaska, the Yukon and the Kuskokwim. The lowland delta region is roughly the size of Kansas

(Barker, 2010). The region's central hub village is Bethel. The village of Bethel is a bush community, meaning no roads connect Bethel to other major cities in the state. The Yukon-Kuskokwim Delta is 500 miles west of Anchorage and is accessible only by aircraft.

The Yup'ik Eskimo people are among the largest population of Alaska Natives in Alaska. Approximately 23,000 Yup'ik Eskimo live scattered among the 56 villages which range in populations from 80 to 1,000 persons each (Fienup-Riordan, 2007). The population of Bethel, according the 2010 United States Census Bureau (2012), is 6000 persons with the majority (65%) being Alaska Native/American Indian. In addition, according to the United States Census Bureau (2012) there is varied cultural diversity of persons residing in Bethel being listed as White (23.3%), persons reporting two or more races (7.3%), Asians (2.5%), Hispanic/Latino (2.2%), African Americans (0.9%), and Native Hawaiian/Pacific Islander (0.4%).

The subarctic tundra environment that is the Yukon-Kuskokwim (Y-K) Delta and the home of the Yup'ik Eskimo is a rich, giving, and sustaining environment. The cyclical nature of plants and animals provides sustenance of body and mind, in thought and deed (Fienup-Riordan, 2007; Kawagley, 2006). The seasonal variation in vegetation, fowl, fish, and mammal has provided the Yup'ik Eskimo a relatively stable and settled life. Today seasonal camps and winter settlements continue to line the rivers and connect villages and communities.

Much of what is known about the cultural lifeways of the Yup'ik Eskimo has been collected and disseminated by Anne Fienup-Riordan who holds a PhD in cultural anthropology from the University of Chicago. Having studied the Yup'ik Eskimo since 1977, she has authored fourteen books and has contributed her expertise to two major museum exhibitions about the Yup'ik Eskimo. Fienup-Riordan lives in Alaska and continues her work and study among the Yup'ik Eskimo.

Ethnohistory

The following quote eloquently depicts the Yup'ik Eskimo people as a culture of stories and words and serves as an appropriate segue to the ethnohistory which follows. "We call ourselves Yup'ik Eskimo or Yupiit [real people]. In our language *yuk* means person or human being. Then we add *pik* [real or genuine]. We are the real people" (John, 1991 cited in Fienup-Riordan, 2007).

Several historical events have wreaked havoc on the Yup'ik Eskimo people. Disease introduced by missionaries and traders decimated the Yup'ik Eskimo population. The smallpox epidemic of 1838-1839 and the influenza epidemic of 1852-1853 annihilated entire villages with an estimated 60% of the Yup'ik Eskimo people dying from these diseases (Fienup-Riordan, 2007). In addition, tuberculosis in the early part of the twentieth century again caused a marked decline in the Yup'ik Eskimo population (Fortuine, 2005). With the loss of Yup'ik Eskimo peoples, the region's non-native population grew exponentially (Fienup-Riordan, 2007).

According to Fienup-Riordan (2007), due to the limited commercial value of the Y-K Delta, missionaries were the predominant first outsiders to stay in the region between the years 1840 and 1888. Moravian missions were established near the Yup'ik Eskimo village Mumtrekhlogamute, which means "smokehouse people" in 1885. Other missions to settle in the area were Russian Orthodox and Roman Catholic (Fienup-Riordan, 2007). Much is written elsewhere about the atrocities inflicted upon the Yup'ik Eskimo by the missionaries (Napoleon, 1996). Language, traditional ceremonies, and subsistence practices were lost to subsequent generations as families were separated when children were sent to boarding schools (Napoleon, 1996). Today the Yup'ik Eskimo are again the predominant inhabitants of the Y-K Delta and the elders seek to renew cultural practices and diminish traumatic outcomes (violence, substance abuse, and suicide) from years of oppression which threaten the health and vigor of future Yup'ik Eskimo generations (Fienup-Riordan, 2007).

Yup'ik Eskimo Worldview

For the Yup'ik Eskimo the world exists on a continuum with no demarcation or delineation between reality and dreams, life and death, or beginning and end (Burch, 1988; Fienup-Riordan, 1990, 2007; Kawagley, 2006). Cyclical energy exists in all things. Ceremonies and ceremonial practices all relate one to the other.

The Yup'ik Eskimo respect and acknowledge three major spirits. Contained in the wind and the weather, the Spirit of the Air is the most powerful permeating the whole world and influencing all things. The Spirit of the Sea controls all the creatures of

the ocean (Burch, 1988). A ceremony central to this spirit is the Bladder Festival. The souls of the seals are believed to be contained in their bladder and returning the bladder to the sea allows future seals rebirth (Fienup-Riordan, 1990, 2007). The Spirit of the Moon is believed to influence all land animals. While reverence to these spirits is practiced the Yup'ik Eskimo do not worship them; the spirits are appeased and in turn would direct caribou or the whale to be taken by the hunter (Burch, 1988).

The Yup'ik Eskimo universe is acknowledged as always in flux and always unified into one being. The cycle of death and rebirth is perhaps best exemplified by the ceremonial hooped mask. The hooped mask consists of concentric rings called *ellanguat* meaning "pretend or model cosmos" (Fienup-Riordan, 1990, p. 59) which encircles the mask. The central features of the mask are the eyes of awareness. More than a metaphor, the eyes allow a view beyond this world and into another (Feinup-Riordan, 1990). The masks are each unique to the particular spirit or cyclical process the mask embodies. The concentric rings and eyes of awareness allow one to see into the spirit world and to be seen by the spirit world, thus making one capable of receiving spiritual knowledge and transformation (Fienup-Riordan, 1990, 2007).

Fienup-Riordan (1990, 2005, 2007) noted that much of the Yup'ik Eskimo way was lost during the last 100 years as the *Kass'at* (white people) with their missionaries and schools replaced the traditional teachings, forbad speaking Yup'ik Eskimo language, and disallowed traditional ceremonies; citing them as pagan rituals. Today, the elders are uniting, especially Yup'ik Eskimo elders of the Y-K Delta, to revive the traditional

ways. Negotiated meaning between Yup'ik Eskimo cosmology and Judeo-Christian worldview has transformed forever the ways and the understandings of the Yup'ik Eskimo (Fienup-Riordan, 1990, 2005, 2007).

Kinship and social factors. Fienup-Riordan (1990, 2005, 2007) has drawn together the most comprehensive and detailed collection of *qanruyutet* (adages, words of wisdom, and oral instruction) known by the Yup'ik Eskimo elders of the Y-K Delta. Throughout Yup'ik Eskimo history *qanruyutet* has served as the foundation for the relationships between men and women, parents and children, siblings, cousins, neighboring villages, and non-Natives. "We talk because we love you" (John, 2000 cited in Feinup-Riordan, 2005) is the central ideology of historic Yup'ik Eskimo teaching. Teachings center on humility and compassion to all living things, promoting tolerance (Kawagley, 2006). Fienup-Riordan (2007) noted Yup'ik Eskimo elders' belief that love and guidance as discipline are lost to the Yup'ik Eskimo of today. However, great efforts are underway to return to the traditional language and the traditional teachings. While the knowledge and wisdom amassed is great, what follows here is a glimpse into the traditional Yup'ik Eskimo worldview, cultural values, and beliefs most relevant to this study.

Males. Seasonal settlements dictated village cohabitation. During the winter settlements males and females lived together. During non-winter seasons the males and females lived separately. The *qasgi* (communal men's house) was a large round semi- subterranean log and sod structure where the men ate, slept, worked,

entertained, and bathed (Feinup-Riordan, 2007). Most importantly it was here that the men imparted *qanruyutet* to the boys. The *qasgi* was the school and the men were the teachers. Boys were considered men when they grew whiskers. Skills and responsibilities were taught according to capability and perceived receptivity, not age.

The *qasgi* served other important functions to the village and to the males of the village. It was in the *qasgi* that all major village decisions and discussions occurred and where ceremonies and celebrations took place. The *angalkut* (shaman) tended to the sick and performed rituals for fair weather and successful hunts (Feinup-Riordan, 2005, 2007). It was here that all moral instruction for a properly lived life was watched, listened to, and learned (Feinup-Riordan, 2005, 2007). Over the decades, the *qasgi* gave way to single family dwellings, churches, and the traditional classroom. Elders, according to Fienup-Riordan (1990, 2005, 2007), believe that the social problems (domestic violence, suicide, substance abuse) which plague the Yup'ik Eskimo today are a result of losing the teachings with the loss of the *qasgi*.

Females. Fienup-Riordan (2005, 2007) noted that females received all instruction from observing their mothers and all other female members of the village. The *enet* (sod house) was the female dwelling. It was here that females and children lived and worked. Boys at the age of five left their mother's dwelling to live in the *qasgi* with the men. Girls were encouraged to learn how to work. Just as their male counterparts learned, females observed work until they could function independently. Age did not define maturity; rather the ability to carry out tasks independently and in a

manner which did not require constant instruction defined maturity. For females this stage usually coincided with the first menstruation (Fienup-Riordan, 2005, 2007).

Parents and children. The most essential of all human relationships was that between the parent and child (Fienup-Riordan, 2005, 2007). All responsibilities and rules for living, surviving, and functioning as a member of society and for a properly lived life were taught lovingly but firmly. While males and females received gender specific instruction the overriding goal of either parent was to impart obedience, compassion, and reverence for elders (Fienup-Riordan, 2005, 2007). It is held that children were capable of learning before they could speak. Even today parenting is believed to be a reciprocal relationship. Children learn through what they observe and how they are taught; parents must embrace this responsibility, watch over them closely, and not ignore them (Fienup-Riordan, 2005, 2007). The Yup'ik Eskimo believes that the child reflects the parent.

Elders. Elders were the central figures in educating Yup'ik Eskimo children and youth. Today elders are still respected for their wisdom. Wisdom is passed down to children through stories and children learn through observation. The elders instruct with carefully chosen words (Fienup-Riordan, 2005, 2007). It is understood that knowledge is not property to be owned by the few, but rather is the shared experience gained by engaging in the world and with others. Elders are cognizant of what the young people need to know and of how the young people need to learn (Fienup-Riordan, 2005, 2007).

Moral instruction. The elders who shared stories with Fienup-Riordan (2005, 2007) noted that *qanruyutet* would guide lives. To ignore *qanruyutet* would invite disaster for people following their own minds and acting on their own thoughts. In the past children were taught all moral rules, guidelines, and standards: how to behave as children, how to behave as adults, and how to behave as either a wife or a husband throughout their lives. Moral instruction provided all things needed to live a proper life. For males moral instruction was a part of the *qasgi.* When elders spoke all worked stopped and all persons listened. Today the Yup'ik Eskimo believes that one should speak no more than is needed. Moral code is complicated and requires a lifetime of learning to understand. Teaching and learning is a lifelong responsibility and pursuit (Fienup-Riordan, 2005, 2007).

Ceremonies. Yup'ik Eskimo ceremonies began at the end of summer and continued throughout the winter culminating with the beginning of the harvest and hunting season in the spring. While many of the traditional ceremonies have changed (influenced by modernity or religious practices) the pattern of acknowledgment and preparation continues today. As with all things inherent to the Yup'ik Eskimo worldview, the cycles of "spiritual constancy" (Fienup-Riordan, 1990, p. 63) are symbolized in naming practices, marriage patterns, and observances, (i.e., Bladder Festival, Feast for the Dead). Important to this study are practices pertaining to rituals after death. In the first, ritualistic "erasing" (Fienup-Riordan, 1990, p.58) after death, "the bereaved circled the outside of the house in the direction of the suns' circuit, at the

same time rubbing its walls all around with a whetstone to close the entrances and make them invisible to the spirits of the dead" (Fienup-Riordan, 1990, p.58). Five days after the death mourners encircled the grave of the deceased again in the direction of the sun's path in order to send away the spirit of the deceased. Finally, the name of the deceased was given to the next born relative (Fienup-Riordan, 1990).

In summary, the worldview of the Yup'ik Eskimo and the ceremonial practices epitomize the cyclical nature of life and death. Research is needed to discover the present day meanings, beliefs, patterns, and practices at end-of-life among Yup'ik Eskimo so that nurses promote culturally congruent care. Observation and oral instruction are the predominant forms of learning and sharing knowledge. Both women and men share the responsibility, with elders the ultimate knowers of past culture expressions, meanings, patterns, and practices of Yup'ik Eskimo lifeways.

End-of-Life Literature

In consideration of the NIH/NINR emphasis on end-of-life care research and the culture specificity recommended in this study, I conducted a broad review of the death and dying literature. Included in the search were anthropology, health sciences, philosophy and religion, psychology, and sociology databases. Specific databases searched were Philosophers Index, American History and Life, electronic Human Relations Area Files (eHRAF), CINAHL, Medline/PUBMed, Web of Science, PsycINFO, and Social Science Electronic Data Library. Databases were searched for books, peer reviewed research articles, feature articles, and editorials with no delimitation in the

year of publication which allowed for seminal foundational works. Key words used were Alaska Native, Indian, death, dying, end-of-life, ethical dilemmas, professional dilemmas, barriers, and end-of-life.

Article abstracts were reviewed for relevance and reference lists were scanned for additional articles or books. The following literature review is comprised of research articles, scholarly journal feature articles, editorials, an unpublished manuscript, and one book. Inclusion criteria included: (a) research, opinion, or editorial works published in peer-reviewed journals/books; (b) works addressing dying or end-of life from a broad perspective on death and dying, cultural perspective, or ethical perspective, and (c) works written in English. International journals were included. Four emergent themes organized the review: (a) death and dying, (b) cultural experiences at end-of-life, (c) contextual experiences at end-of-life, and (d) ethical and professional dilemmas at end-of-life. The majority of the studies were qualitative and atheoretical; where research was theory guided it is clearly explicated. Finally, I summarize the identified gaps in the literature to support the need for my study and to support the use of the Culture Care Theory and the ethnonursing research method.

Death and Dying

Over the past six decades, improved public health measures and medical advances have increased longevity, improved health, and increased the incidence of life with chronic illness (Lynn, 2005). Historically, persons died in childbirth, from childhood illness, or from acute illness (Gates, 1988; Kaufman & Morgan, 2005; Kübler-Ross, 1969).

Presently, persons survive what once was life-threatening. For some, increased longevity is marked by years of debilitating chronic or terminal illness preceding death (Lynn, 2005). Olshansky and Ault (1986) referred to increased longevity marked by chronic illness as the fourth stage of epidemiologic transition.

Gates (1988) and Hardwig (2009) and Seno (2010) noted that for non-medical persons the predominant orientation to death is one of human experience, an inevitable and inescapable conclusion of living. Conversely, healthcare providers view death as a medical failure (Gates, 1988; Hardwig, 2009; Segal, 2000). Furthermore, care of persons both during dying and at the time of death has been delegated to professionals, has moved from the home to the hospital, and as a result, has become unfamiliar to family members (Hardwig, 2009).

In summary, the changed environment of dying is a relatively new phenomenon in healthcare. Philosophical, ethical, and cultural debates among providers and within society require time to occur, evolve, and translate back into society and healthcare practice (Gates, 1988; Hardwig, 2009). Not surprisingly, patients and healthcare providers struggle to find their way in this new and evolving culture of dying and death. Research directed to discover and uncover the intricacies of culture care needs at end-of-life will add to the debates and discussions.

Patient Perspectives of Death and Dying. Examples of patient and family experiences of death and dying over different time periods are abundant in the literature (Hardwig, 2009; Kübler-Ross, 1969; Segal, 2000; Seno, 2010). Differences in

the stories are dependent on when, where, and how the death transpired. Stories of death and dying recalled from experiences four to five decades ago were devoid of hospitals, machines, treatments, or protocols (Hardwig, 2009; Kaufman & Morgan, 2005; Kübler-Ross, 1969; Segal, 2000). Persons died in the home surrounded by family and friends. The decisions of the dying were respected, not demeaned, and beliefs and values were not violated (Hardwig, 2009).

Forty to fifty years ago death was the imminent fate of illness (Segal, 2000). Elderly persons who became too ill to get out of bed would inevitably develop pneumonia and in the absence of antibiotics often died. Existing treatments were not effective. In other instances, patients who experienced traumatic lethal injuries were told as much; a patient decision to not seek further medical attention and to be returned to their home to die was respected (Segal, 2000). The patient was returned to the home, surrounded by family and friends, and after death, affairs were arranged. Children were not excluded from the death and dying process. Death was not a mystery, a misery, or a burden; death was the inevitable and accepted consequence of life (Hardwig, 2009; Kaufman & Morgan, 2005; Kübler-Ross, 1969; Segal, 2000).

To summarize, today death and dying is generally relinquished to the medical facility. Some patients and families refuse the technological and medical advancements which temporarily cheat death. Other patients and families welcome all medical interventions at end-of-life. Healthcare providers struggle to navigate with the family

and client between these two positions while remaining cognizant of their professional scopes of practice and their philosophical positions.

Healthcare Provider Perspective of Death and Dying. Healthcare providers experience a dilemma when the efficacies versus the humanity of technological advances are questioned (Mohammed & Peter, 2009). End-of-life discussions with patients and family members are never easy conversations to initiate or navigate being complicated by personal, professional, and ethical components individualized to the provider. Furthermore, as Quinn et al. (2012) observed in their ethnographic study in a northwestern urban intensive care unit, family roles complicate healthcare provider communication processes. Kuhl (2010) identified three key components which complicate end-of-life discussions for healthcare providers. Personal discomfort may arise from previously unresolved attitudes towards death and dying. In hospital environments personal connections can be a luxury but are a necessity when the news to be delivered is life altering. For the healthcare provider, introspection is vital. Kuhl (2010) suggests that mentorships and role modeling with skilled professionals is needed to gain a deeper understanding of our own mortality.

Seno (2010) adds that healthcare providers need to be more than physically present when caring for patients and families at end-of-life; families need providers to be authentic in their presence. Knowing the self and reflecting upon personally held beliefs may lead to becoming comfortable with death allowing for a more present *being with* during end-of-life encounters. Perhaps much of what complicates end-of-life

conversations between families, patients, and healthcare providers is each individual's inability to find a level of negotiated comfort with death.

In the hospital environment the discussion about end-of-life is not seen as a priority, and, at the most basic level, healthcare providers may be deficient in training or insight, in this case cultural insight, to navigate the conversation with confidence (Seno, 2010). In addition, Mohammed and Peter (2009) note that dying in a "biomedical culture" (p. 301), (the culture inherent to the hospital, physicians, and nurses) adds yet more layers which further complicate end-of-life discussions.

Healthcare providers often initiate end-of-life conversations with terms foreign to the patient or family member. Words like *inotropes, resuscitation, intubation*, and *levels of care* (i.e. *do not resuscitate* versus *do not intubate*, or *cardiopulmonary resuscitation without medication*) sound like a foreign language to patients and family members. Medical jargon often does more harm than good by unknowingly inflicting emotional pain onto patients and family by addressing the disease rather than the patient (Kuhl, 2010).

In summary, healthcare providers need to ask the difficult questions at end-of-life in words recognized as genuine and in concert with patient and family needs. What do dying patients want at end-of-life? Whether or not unwittingly insensitive end-of-life conversations cause further emotional pain and suffering or assist the patient and family to "embrace life while they prepare to die" (Kuhl, 2010, p. 1707) depends a great deal on the content and delivery of the conversation.

Culture Care Experiences at End-of-Life

Dying and death is a unique process and dependent on the meanings held by each individual/family unit. Evidence indicates that many patients appreciate healthcare providers who acknowledge cultural beliefs and practices (Chochinov & Cann, 2005). According to Chochinov and Cann (2005) the physical, psychological, or the spiritual needs of the patient cannot exist at the exclusion of the others. A holistic unified perspective which honors the whole person requires caregiver sensitivity and cultural expertise.

Baydala et al. (2006) noted, in their qualitative data based study with First Nation Canadian Aboriginals, that death was viewed as a journey, one part of the larger process of life. It was not an end, rather a new beginning. Participants noted the harshness of the words, *death* and *dying*. Culturally appropriate terms identified were *crossing over* and *transitioning to crossing over*. Life for the First Nations Aboriginal were explained as a series of rituals that continued into dying and after death. *Rituals* were differentiated from *routines* in that rituals, while they might follow similar patterns or processes, require reflection. Storytelling among First Nations Aboriginals offers immortality and expresses caring related to end-of-life care practices.

The most recent knowledge regarding Alaska Native "traditional ways of caring for the dying, current values and preferences surrounding death" (DeCourtney et al., 2010, p.23) was reported from focus group discussions obtained over an eight year period in six different locations of both remote and urban Alaska. Eighty-four elders

participated. Death was described as an accepted part of life. The family, which included the community, was described as the primary providers of care for the terminally ill. Among Alaskan Natives this was expressed as an honor, an obligation, and a duty. Elders were not sent away. Village survival required community cohesiveness. The result of the work was assembled into a just-in-time handbook which supports caregivers in the home.

Culture care expressions, meanings, patterns, and practices at end-of-life are different across cultures. Culture care is multifaceted and complicated. While culturally specific examples of end-of-life care expressions, meanings, patterns, and practices vary across cultures little research was located which examined the perspective among Alaskan Natives exclusively and Yup'ik Eskimos specifically.

Family. Born, Greiner, Sylvia, Butler, and Ahluwalia's (2004) qualitative focus group study examining end-of-life care among low income African Americans and Latinos identified comparable themes. Both groups identified a strong familial presence as paramount during end-of-life care. Lessening caregiver burden and strain was deemed important for caregiver resilience. Both groups discussed issues related to burdening family members.

Additionally, Maddalena (2009) stated that the growing diversity of American society challenges the provision of holistic healthcare. Cultural beliefs and values influence all parts and processes of a person's life. Complexities include the presence of family at end-of-life, involvement of family members, community members, or the

absence of the same in decision-making (Maddalena, 2009). Knowing to whom questions should be addressed complicates the end-of-life care. In many cultures questions are directed to an elder or a spouse as opposed to the patient. This requires establishing relationships with the patient, the family, and in some instances the community.

The roles of family members can be diverse and complicate encounters at end-of-life (Quinn et al., 2012). Researchers observed several informal family member roles during end-of-life encounters which complicated the decision-making process in an urban intensive care unit. Quinn et al. (2012) noted that healthcare providers' ability to understand and recognize family member roles positively effects interactions. In summary, acknowledging the role of family members, elders, and the patient is paramount to culturally congruent end-of-life care. Cultural familial variations can complicate many facets of end-of-life decisions. Therapeutic relationships allow for discovery leading to common understanding and meanings assigned to illness, treatments, and death and dying (Born et al., 2004; Maddalena, 2009).

Gender. In order to reveal and ultimately understand the complexities of diverse racial, ethnic, and gender differences related to end-of-life care, Duffy, Jackson, Schim, Ronis, and Fowler (2006) explored the preferences among Arab Muslims, Arab Christians, Hispanics, African Americans, and Caucasians. Among the cultures, differences in family responsibilities and expectations, amenability of nursing home and hospice care, degree of medical intervention, advance-directive and living wills, and

assisted suicide were appreciated. In addition, differences within the groups by gender were examined.

Women were discovered to be more culturally grounded, were more accepting of touch and closeness, and valued prayer (Duffy et al., 2006). In addition, Duffy et al. (2006) observed that women were more likely than men not only to have living wills and durable powers of attorney, but also a desire to see that arrangements and unfinished business were addressed. African American males and Caucasian females were more likely to distrust physicians. The authors cautioned that while similarities exist among cultures, gender differences do exist and careful assessment of patient specific needs is necessary for culturally congruent end-of-life care.

Gender differences influence individual and family dynamics. How persons relate to each other or in group processes impacts the division of responsibilities, care choices, and the relationships between persons/family and healthcare providers.

Religiosity and spirituality. Spirituality is individualized and contextual. A qualitative personal narrative (Baydala et al., 2006) explored First Nation Aboriginal perspectives of end-of-life and dying from the stories shared by two persons. First Nations Canadian Aboriginal's shared the belief that words carry power and can "create emotional resonance" (Baydala et al., 2006, p.166). To die well was to live well. The participants revealed that it was how one lived from what they were taught which prepared them for the final moments. At the end, if one could state that dying was all that was left then living was done well. Among the Aboriginal First Nation participants

in this study grieving was identified as individual and related to voids in patterns of living and no longer living with the person who died. Grieving too hard affects living by trapping energy both for the one deceased and the one that continues to live.

In their qualitative study of Jewish patients and families, Bonura et al. (2001) illustrated the importance of religious practices and culturally congruent care at the end-of-life. Findings revealed strong culturally and religiously held beliefs regarding end-of life care. Seven culturally relevant premises emerged from the interviews:

1. caring for the ill and dying is not an expected cultural duty, it is religious law (p. 214)
2. end-of-life care extends beyond the dying family member (p. 212)
3. attentive end-of-life care demonstrates the value of life, acknowledges self-worth, and improves the quality of life (p. 213)
4. knowledge is valued from a cultural and religious perspective (p. 214)
5. religiously held beliefs regarding the afterlife influence attitudes concerning suffering (p. 214)
6. Jews oppose the term hospice, many believe the word to mean assistance with death and to assist with death runs counter to the belief that the body is a gift from God (p. 217)

7. the expression of suffering is linked to historical suffering and is carried out ritualistically during illness, at the time of death, and after death (p. 213).

Jenkins, Lapelle, Zapka, and Kurent (2005) examined end-of-life care among two groups of African Americans from a southeastern United States inner city. Findings revealed a strong belief in God and in miracles while underscoring the need for health care provider sensitivity to these beliefs. Similarly, the African American and Latino participants in Born et al.'s (2004) qualitative focus group study emphasized religious convictions and matters of spirituality as the major source of comfort and coping. The underlying theme of religiosity and spirituality exists throughout the literature (Baydala et al., 2006; Bonura et al., 2001; Born et al., 2004; Jenkins et al., 2005). Western healthcare providers' interest in the culturally situated spiritual beliefs and practices at end-of-life is experiencing resurgence. Spirituality goes beyond religion, assists in identifying meaning at end-of-life, provides a source of strength, and provides well-being to support persons. Cultural specificities are complex across cultures, within cultures, and not transferrable from culture to culture.

Decision-Making. Decision-making at end-of-life is complex involving for example but not all inclusive, advance-directives, treatment decisions, and withdrawal treatments. Western medicine emphasizes patient autonomy and truth telling in decision-making (Thomas, 2001). Not all cultures follow this level of decision-making and there are often other culturally embedded factors which influence decision-making.

Culture specific complexities exist as emphasized by Chan and Kayser-Jones (2005) in their study of end-of-life care among elderly Chinese persons in nursing homes. Hope was found to be a prominent belief influencing decision-making. Complicating matters further is the intermingled intangibles influencing decision-making (Thomas, 2001). Among these are the level of acculturation, religious preferences and the weight of religion on decision-making processes, fluency of language, and the reliance on or preference of informal or formal caregivers. Thomas (2001) added that the Western philosophical focus at end-of-life is to alleviate suffering, enhance coping, and to potentiate the acceptance of eventual death.

In summary, Western medicine emphasizes patient autonomy and truth telling. However many cultural groups avoid discussing death, discussion is seen as a negative force, disrespectful, and can lead to depression and hopelessness. Decision-making is further complicated by cultural preferences related to family involvement. It is important for healthcare providers to understand what influences decision-making processes for their patients and families.

Barriers. Barriers to end-of-life care identified in the literature included miscommunication, language barriers, distrust, and geographical barriers. Communication barriers are a prominent theme within the literature (Born et al., 2004; Chan & Kayser-Jones, 2005; McGrath & Phillips, 2008; Tulsky, 2005).

Communication barriers. In their study among Chinese nursing home residents, Chan and Kayser-Jones (2005) identified language barriers in their study among Chinese

nursing homes residents as pivotal to matters of socialization with others and in expressions of healthcare needs. Communication barriers led to feelings of isolation and affected caregiver burden, in that family members felt compelled to be involved in care, to be present 24 hours a day (Chan & Kayser-Jones, 2005).

Tulsky (2005) stated that the success and failure of communication contributed to patient and family complaints about the healthcare providers. Communication between patients, their family members or care providers, and healthcare providers can be enhanced and improved. Tulsky (2005) noted that future research is needed to address the "predictors of patient preference for information" (p. 100). Most importantly, the impact of end-of-life communication behaviors on patient outcomes has yet to be examined.

McGrath and Phillips (2008) identified how language barriers increased fear and added to feelings of isolation among Australian Aboriginals relocated from their villages to urban hospitals for palliative care. Likewise, Born et al. (2004) noted that an inability to communicate secondary to language disparities was a predominant perceived barrier among the Latino group, while mistrust of the health care system in general was a predominant perceived barrier among the African American group. Much of this mistrust can be traced to previous research conducted among minorities resulting in a fear of conceding life and death decision-making power (Born et al., 2004).

In summary, the inability of healthcare providers to understand language or appreciate the diversity in descriptors often leads to inadvertent substandard care.

Racial and cultural barriers create communication disconnect between patient and provider. Research directed to discover the descriptions embedded in the expressions, meanings, patterns, and practices related to end-of-life inherent in cultures offers the opportunity to bridge gaps in communication.

Geographic. Geographical barriers to end-of-life care often exist. Hotson, Macdonald, and Martin's (2004) qualitative descriptive study examined palliative care services available to rural dwelling Aboriginals in northern Manitoba, Canada. The purposes were to: (a) define palliative care services, (b) examine beliefs and attitudes regarding death, dying, and end-of-life care, and (c) investigate barriers to palliative care services. Analysis of the informant interviews revealed that Aboriginals prefer to receive palliative care at home. Geographic barriers to palliative care included, isolation limited available specialists, limited support in the absence of the primary caregiver, and lack of resources led to misunderstandings regarding palliative medication regimes.

McGrath and Phillips (2008) also examined geographical influences on end-of-life care and identified psychosocial and financial strain among Australian Aboriginals receiving palliative care services provided in urban settings. Such care required the relocation of the terminal patient. In this qualitative study interviews revealed many of the participants were relocated from their village to a large metropolitan hospital where they often received the initial terminal diagnosis. The predominant theme identified was one of fear. Patients and family members expressed multiple fears which created barriers to optimal end-of-life care. Fears revolved around a fear of travel, people,

equipment, and food. In addition, language barriers increased fear and added to feelings of isolation. Financial burdens were identified by both patient participants and family participants as fearful barriers to end-of-life care.

Understanding end-of-life culture care expressions, meanings, patterns, and practices and applying this understanding to nursing care is paramount to providing culturally congruent end-of-life care when geographic obstacles influence care. A new and foreign environment can create fears and result in isolation. Relocation should be considered an alternative rather than a routine intervention. Furthermore, treatment considerations should incorporate the cultural context in which they exist.

Contextual Experiences at End-of-Life

The majority of literature reviewed indicates that patients and families struggle regardless of whether end-of-life care is received in the hospital or in the home (Jenkins et al., 2005; McGrath & Phillips, 2008; Porock, Pollock & Jurgens, 2009; Teno et al., 2004).

Hospital. Porock et al. (2009) examined intimacy, privacy, and the experience of dying in public (open hospital wards) in their qualitative study of gerontology ward patients in the United Kingdom. They discovered that the hospital setting altered cultural norms of grieving and emotional distress. Public space altered personal and private conversations. Professionals observed inhibited psychosocial support and professional care. All participants found comfort, clear physician-to-patient communication, hope, optimism, and acknowledgment of spirituality/religiosity

important. Furthermore, Porock et al. (2009) noted that professional care givers used Western cultural norms of autonomy and self-control to evaluate patient and caregiver response to grief and emotional distress.

McGrath and Phillips (2008) in their qualitative study conducted open-ended interviews with 72 Australian Aboriginals in four regions of Australia's Northern Territory to learn about current palliative services, how services might be modified to deliver care congruent with cultural lifeways, and about services not yet provided. Findings indicated a need to support spiritual perspectives through the emphasis of positive spiritual attributes of the Aboriginal culture. It was discovered that varying degrees of tradition exist among individuals. Contemporaries live less traditional lives yet remained grounded by their traditional values and beliefs. Participants shared that learning is an earned right among Aboriginals and non-Aboriginals. Aboriginals did not *offer* information which is different than not *sharing* information. Hesitance to teach without having earned the right to learn is expressed by the Aboriginal perspective that traditional healers generally are not respected by the majority of non-Aboriginal healthcare providers. Respectful sharing leads to learning. Culturally congruent care requires collaboration and integration.

Teno et al.'s (2004) retrospective study examined the responses of family members of deceased family members in a large (n=1,578) multi state study. Significant findings indicate that family member satisfaction with end-of-life encounters occurred in the home more often than in the hospital or nursing home. Unmet client needs

caused most dissatisfaction. Among these unmet needs were physiologic needs (i. e. shortness of breath, inadequate pain control) and psychological needs (i.e. emotional support and communication).

Hospice. Gelfand et al. (2001) identified patterns in their qualitative study which examined end-of-life attitudes among minimally acculturated Mexican-Americans. Findings indicated that end-of-life care is considered a family priority. Family members viewed reliance on hospice or an inability to care for one's own family member as an embarrassment. Hospice, as perceived by family members, was to be used for health care related needs such as medical treatments and procedures. McMillan (2005) noted that as health care moves out of the hospital and into the home caregiver burden and stress needs examination. The benefits of lessened caregiver burden were poorly understood by families and yet important to the patient at end-of-life (McMillan, 2005).

Born et al. (2004) identified barriers to hospice care in their qualitative study of end-of-life care among low income African Americans and Latinos. Predominant themes identified by both groups included access to services, cost, and an incomplete understanding of what hospice care included or how services could be obtained.

Gates' (1988) ethnonursing study compared the universalities and diversities between the hospital and hospice environments for persons at end-of-life. Universal patterns included "caring as closeness" (p. 11) between the staff and the patients. Both environments potentiated the development of long term relationships and fostered community cohesiveness. The hospital and hospice staff cared for each other as well as

for patients and family. Descriptions of caring among staff included sharing of stories, foods, and humor.

The diversities between the hospital and the hospice discovered by Gates (1988) included the marked hierarchal and routine nature of the hospital as contrasted to the more horizontal and fluid nature of the hospice environment. Descriptions of hospital environments included cure orientations to care as opposed to the care orientation of the hospice environment. Touch in the context of care delivery in the hospital contrasted sharply with touch in hospice where it was discovered to be spontaneous and non-circumstantial. Sadly, rituals related to dying in the hospital addressed professional activities, forms and procedures, rather than meaningful or beneficial care to the patient and family.

Care provided in the hospital setting challenges cultural boundaries of privacy and respect. In addition and to further complicate matters, the complexities of different cultural views of hospital care and home care require consideration. As out of hospital end-of-life care options become more prevalent and preferred the caregiver educational and supportive needs demands examination. It is necessary to closely examine the culture care within an organization (whether hospital or hospice) for meaningful and beneficial end-of-life care for individuals and families. Culturally diverse populations challenge the complexity of these educational and supportive measures for organizations.

Ethical and Professional Dilemmas at End-of-Life

In her essay, Higginson (2005) noted that cultural influences shape patient and family perceptions of quality at end-of-life care. Physician and nurse perceptions of quality end-of-life care versus patient and family perceptions of quality end-of-life care is poorly understood and posited to be complicated by the dearth of available research into culturally sensitive standards of care.

Hampton et al. (2010) examined five First Nations Aboriginals elders and end-of-life care and asked specifically, "What would you like non-Aboriginal health care providers to know when providing end-of-life care for Aboriginal families?" (p.6). The purpose of this qualitative community action study examined the beliefs, meanings, and practices important to First Nations Aboriginals about end-of-life care. Six themes organized the narrative: (a) completing the circle, (b) gathering community; preparing for death, (c) care and comfort, (d) moments after death, (e) grief-wake-funeral, and (f) messages for health care providers.

Findings indicated that different perspectives of end-of life care among Aboriginals and non-Aboriginals often lead to barriers in culturally congruent or appropriate care. Barriers identified involved communication, discrimination secondary to misunderstandings, and institutional policies that inhibited traditional lifeways and customs of First Nations patients and their families. Suggestions to improve care included larger rooms to accommodate family, the alteration of hospital policies to allow for traditional rituals (body preparation, the use of herbs), cross-cultural

education for healthcare providers, and availability of cultural resources for healthcare providers (Hampton et al., 2010).

Crawley (2005) noted that the demographic majority shifts occurring in the United States and the heterogeneity of cultures challenges the provision of culturally congruent end-of-life care by providers. Studies which explore and examine bias, preferences, and prejudices which compromise the integrity, dignity, and quality of end-of-life for patients of diverse cultural backgrounds potentiates culturally congruent knowledge. Understanding culture care expressions, meanings, patterns, and practices of end-of-life care and applying an understanding to nursing care promotes culturally congruent care.

Additional research needs to examine institutional practices that promote or inhibit traditional lifeways and practices. Among those practices that promote traditional lifeways and practices is the provision of large rooms where families can gather; amendments to institutional policy which inhibit traditional spiritual practices that include burning of herbs; and most importantly, cross cultural education and resources for non-Aboriginal care providers.

Chapter Summary

Culture care specific examples of end-of-life care expressions, meanings, patterns, and practices vary across and among cultures. The perspective among Yup'ik Eskimo needs to be examined. The multiple religious influences, little known cultural

lifeways, and complicated geography necessitate further investigation to appreciate an understanding of Yup'ik Eskimo end-of-life culture care.

At the end-of-life religion and attention to cultural attitudes and care beliefs are different across and among cultures. Dying and death are discovered to be a unique process and dependent on the meanings held by individuals, families, and communities within the context of their culture. No studies were identified which explored end-of-life care among Yup'ik Eskimo in community settings using the Culture Care Theory and ethnonursing research method. Considering that Alaska Native tribes differ among five different geographic regions of Alaska each with unique linguistic, social, and clan variations among and between regional tribes (Alaska Native Heritage Center Museum, 2008), discovery contributes to what is known and offers insight about what is unknown related to end-of-life care for Yup'ik Eskimo. Discovery promotes culturally congruent professional nursing practices which support the culture care expressions, meanings, patterns, and practices related to end-of-life care among Yup'ik Eskimo.

Chapter 3

Method

The ethnonursing method is congruent with the purpose of the study which was to discover the end-of-life culture care expressions, meanings, patterns, and practices among Yup'ik Eskimo. Leininger (2006a) developed this method to expand transcultural nursing knowledge particularly when little is known about a given phenomenon. The distinctiveness of the theory lies in its broad, holistic focus serving to unveil diversities and universalities inherent within and among cultures. The method was used to uncover largely covert, culturally embedded lifeways associated with and surrounding Yup'ik Eskimo end-of-life care. As in other qualitative methods, the ethnonursing research method requires the suspension of *a priori* judgment (Leininger, 2006b; Lincoln & Guba, 1985).

The ethnonursing method is rigorous and systematic. It is well-designed to reveal the emic (generic/folk) and etic (professional) perspectives of culture care. In this way newly discovered culture care phenomenon can be compared and contrasted between the two perspectives leading to more culturally congruent care practices. The method focuses on the importance of the people's way of knowing through the use of direct naturalistic inquiry (Leininger, 2006b).

Research Enablers

Enablers were developed by Leininger (2006b) to assist ethnonursing researchers to explicate in-depth culture and care knowledge. The enablers used in this study were

the (a) Sunrise Enabler (Appendix A), (b) Stranger to Trusted Friend Enabler (Appendix B), and (c) Observation-Participation Reflection (OPR) Enabler (Appendix C). The Sunrise Enabler, a cognitive map of the theory, assisted me to maintain a broad focus, to develop the domain of inquiry, and to consider the many factors which influence culture care expressions, meanings, patterns, and practices. The Stranger to Trusted Friend Enabler and OPR Enabler assisted in the process by which I moved from a completely observatory role to an increasingly more participatory and interactive role, and finally to reflection. The Stranger to Trusted Friend Enabler was useful in self-assessment and reflection as my relationships changed overtime and ensures the authenticity and credibility of the data.

Entrée into the Field

The impetus for this project began in 1997 when I transplanted from Pennsylvania to Alaska. As a nurse in Alaska I have worked exclusively in the intensive care unit and over the past 14 years I have moved from a completely observatory role to an increasingly more participatory role with Alaska Native patients and their families. During this time I also recognized the complexity of healthcare delivery in Alaska, particularly at end-of-life. Since 2009 my curiosity has grown as I have worked exclusively with Alaska Natives. I have witnessed many multifaceted end-of-life care interactions between non-Native care providers and Alaskan Native patients and their families. This long history of living in Alaska and caring for Native Alaskan people provided valuable credibility in being accepted into the Yup'ik Eskimo culture in Bethel.

Over the past two years as part of my early scholarly development I began the process of formal immersion into the Yup'ik Eskimo community using the Stranger to Trusted Friend Enabler. It was during this time that relationships were forged between me and those persons who would later become my gatekeepers and key and general informants. While actual data collection did not commence until official Institutional Review Board (IRB) approval was obtained, this time allowed me to explore the Yup'ik Eskimo community's interest and their participatory role in the study.

After IRB approval was obtained data collection began. My previous professional and social experiences facilitated entry into the research field. It was during this time that I lived with my gatekeepers in the Yup'ik Eskimo community of Bethel. I assumed an increasingly active participatory role with the informants. I relied on the OPR enabler to focus my presence and purpose during this time in order to learn the community context leading to accurate and credible informant data (Leininger, 2006b).

My first encounters transpired quite serendipitously. During one such encounter, a community fair, I was invited by a key informant to assist with meal preparation for a potluck gathering to take place later in the evening. Several women (ages 40 to 60 years of age) were tearing meat from turkeys with bare hands. I followed the lead of my key informant and began to assist with the turkeys. I was introduced to the other women who politely smiled. Once this task was complete one of the women at the table asked me to assist at another station; I learned later from my key informant that I must have made a favorable impression or I would not have been asked to assist.

In Yup'ik Eskimo culture lessons are learned first by respectful observation, listening, and replication. In all instances where I was asked to participate in activities I made sure to follow this pattern of respectful learning. Working alongside Yup'ik Eskimo I discovered experiences and practices inherent in their everyday activities.

The goal of the ethnonursing method is to discover culture care ways of knowing inherent to a people which through established rigor assists the professional nurse to understand culture care expressions, meanings, patterns, and practices of a phenomenon. In this study Yup'ik Eskimos are the knowers of end-of-life care for their people and, as such, were interviewed using an open inquiry guide (Appendix D). The inquiry guide evolved throughout the study as interviews provided new and previously unknown information about recurrent themes, patterns, and descriptors. Initial questions were directed to illicit broad discovery about end-of-life care for Yup'ik Eskimo. As time went on the observations and interviews focused the lens of discovery sharper on the very distinct descriptors which would later lead to recurrent patterns and eventually the themes related to Yup'ik Eskimo end-of-life culture care.

Data Collection

Data collection was extensive and used multiple modes. I collected data in Bethel, Alaska and Anchorage, Alaska. After obtaining IRB approval I spent one week in Bethel which consisted of a general orientation phase to the community and introductions to persons interested in learning more about my study. Observations were recorded as field notes and included attendance at a community fair, a holiday

bizarre and gift exchange, Russian Slavic celebration, and informal gatherings (dinners, breakfasts, and coffee breaks). Formal introductions by informants to new and interested informants incorporated additional forms of data gathering to include email and telephone interviews.

During my time away from Bethel I made a concerted effort to maintain respectful relationships with persons involved in the study. I frequently called, texted, and emailed informants and persons who would later become informants. During this time additional phone numbers or email addresses were forwarded to me as formal introductions to others. In addition, I extended invitations to informants travelling into Anchorage from Bethel. I reciprocated the invitation extended to me: there would always be a place setting at the table. Overall, I spent two years forming relationships and learning of the Yup'ik culture and once IRB approval was obtained I collected data in Bethel, Alaska and in Anchorage, Alaska for three months.

Setting and Participants

The community setting consisted of the Yukon-Kuskokwim Delta, Alaska. The central data collection site was Bethel, Alaska. Some general informant interviews occurred in Anchorage, Alaska. Purposeful sampling was used to obtain informants for this study and was guided by the domain of inquiry (end-of-life culture care expressions, meanings, patterns, and practices among Yup'ik Eskimo) and the inclusion criteria. Participation was voluntary. Any interested informants, male or female, age 18 and older who contacted the researcher for further information and provided consent

participated in the study. Interested informants were identified in the community setting with the help of gatekeepers. The gatekeepers for this study were a non-Yup'ik Eskimo woman and a Yup'ik Eskimo woman. Both gatekeepers are residents and trusted members of the Bethel community. Initially the gatekeepers verbally discussed the study in informal settings in a non-coercive manner both with me and apart from me. The gatekeepers assisted with the identification of potential interested key and general informants and often made formal introductions. Some formal introductions were to persons who now reside in Anchorage, Alaska.

Inclusion Criteria

Key and general informants participated in this study. The number of participants recommended for ethnonursing research studies is 12 key informants and 24 general informants (Leininger, 2006b). I acknowledge variability in informant number with the determining factor being the establishment of ethnonursing qualitative data saturation. Key informants are those persons most knowledgeable about end-of-life culture care for Yup'ik Eskimo. Key informants were men and women over age 18 who self-identified as Yup'ik Eskimo living in the Yukon-Kuskokwim Delta region of Alaska and who were willing to share their views of end-of-life culture care needs.

General informants are not as knowledgeable in the domain of inquiry as the key informants, yet they contributed reflective and confirmatory data about the expressions, meanings, patterns, and practices of end-of-life care among Yup'ik Eskimo (Leininger, 2006b). The general informants in this study were professionals and non-

professionals, employed and unemployed, engaged within the Yup'ik Eskimo culture and who practice with, among, or serve the Yup'ik Eskimo community. Specific occupational information is withheld here to provide for anonymity.

Data collection consisted of participant observation and individual interviews. Interviews were not audio taped. It became apparent in early discussions with gatekeepers and participant observations that recorders were considered culturally incongruent and that conversations and authentic data flowed more freely without the use of a recorder. Interviews lasted in length from 1 hour to 2 hours. The length of time was determined by the informant. Bulleted field notes and quotes were manually recorded verbatim during interviews and immediately after interviews or participant observations. Additional interviews were discussed and determined with each informant on an individual basis. All informants were assigned a number. I maintained two journals: (a) one for my own observations and reflections and (b) one for interview data.

Ethical Considerations

Prior to the initiation of this study I obtained Institutional Review Board Form B (Appendix E) approval from the University of Tennessee Knoxville. Risks inherent to participation in this study were deemed minimal. Informants volunteered to participate and did not receive compensation for participation or penalty for non-participation. Informants received a small gift of homemade cookies for participating. No informants withdrew from the study. Study purpose, risk, benefits, and informant participation

were verbally explained to the informant's satisfaction. The informant's willingness to participate is demonstrated by the signed consent form (Appendix F).

Informant name and information remains strictly confidential. Informants are not identified by name in any field notes, working analysis notes, or final study report. All informant information is identifiable by an assigned number (i.e. K-1 [key informant number one] or G-1 [general informant number one]). All consent forms are filed separately from all other study information (i.e. field notes, working analysis notes). The informant responses remain kept in a locked cabinet in a locked room and on a password protected computer locked in the researcher's office.

I am well-prepared to conduct this study. A registered nurse, I hold a master's degree in nursing and a post-master's certificate in Transcultural Nursing (advanced education of the research method and theory), in addition to being a PhD student. I collaborated with expert mentors and I obtained interest from key stakeholders in the Alaska Native community prior to the initiation of this study. My dissertation committee is chaired by Mary Gunther, PhD, RN an experienced qualitative nurse researcher. Committee members are Sandy Mixer, PhD, RN a certified transcultural nurse expert, JoAnne Hall, PhD, RN an expert qualitative nurse researcher, and Gregory Button, PhD a medical anthropologist whose research interests include communities in crisis, community and community health. Dr Button' geographical areas of research are the arctic and subarctic.

Data Analysis

Data analysis began immediately with the first interview and continued throughout the study. All observations, field notes, and interviews were analyzed using the four phases of Leininger's Phases of Ethnonursing Data Analysis Guide Enabler (Appendix G) for qualitative data. The data analysis enabler assisted me in discovering the end-of-life culture care expressions, meanings, patterns, and practices embedded within the data and establishes rigor of the method.

In the first phase I became immersed in the community and began to identify initial meanings and interpret observations. During this initial orientation phase I was introduced to the community, community members, and participated in community events. The emic foci of end-of-life culture care and my research questions focused observations during this first phase. To maintain a non-intrusive demeanor I maintained a small notebook and did not document in public. I chronicled the events in the privacy of my room. During the first phase field notes were discussed with expert mentors and initial data coding began. Additional questions were developed out of the preliminary observations and interviews.

In the second phase similarities and differences between emic and etic perspectives were identified. Meanings were explored from recurrent components and patterns in the data and observation field notes. Throughout the second phase I worked with expert mentors and confirmed with informants meanings identified. Only after extensive analysis of all data collected and key informant confirmation was

saturation and redundancy of the data considered. This process was arduous and required immersed time in the field with informants. It was also during this time that informants introduced me to persons in Anchorage, Alaska who were considered to be valuable sources of information as general informants.

Saturation of the data and the identification of recurrent patterns or meanings situated within the context of Yup'ik Eskimo end-of-life care was the focus of the third phase. Expert mentor assistance and key informant confirmation of all data ensured ethnonursing qualitative criteria were met during the third phase of analysis.

The fourth phase of data analyses involved the synthesis and interpretation of the data. I focused on the abstraction and confirmation of the major themes related to end-of-life care among Yup'ik Eskimo in their community settings. It is within the fourth phase of analysis that culture care actions and decisions are formulated and confirmed among key informants. To ensure the establishment of an audit trail and to satisfy the criteria of the qualitative ethnonursing method all data were referable back to the raw data, as data collection and analysis occurred concurrently.

Qualitative Criteria for Evaluation

Rigor. With the assistance of expert mentors the attention to rigor as outlined below was met. To ensure rigor the qualitative ethnonursing research criteria of (a) credibility, (b) confirmability, (c) meaning-in-context, (d) recurrent patterning, (e) saturation, and (f) transferability was be addressed throughout all parts of this study.

Credibility. Credibility refers to the "truth, accuracy, or believability of the findings" (Leininger, 2006b, p.76). Data collection was extensive and used multiple modes. I participated in community events, observations were made at community events and during informal gatherings, and I conducted individual interviews. I maintained a reflective journal and participant-observation journal. Data were collected over a period of three months. The informants' stories offered the emic perspective of the domain of inquiry. In addition to stories, observations and the environmental context (community gatherings, ceremonies, or rituals) provided insight about the expressions, meanings, patterns, and practices of end-of-life for Yup'ik Eskimo.

Confirmability. According to Leininger (1990, 2006b) confirmability refers to informant confirmation of the meanings discovered. It was my intent to achieve a mutual understanding of end-of-life care meanings between myself and the Yup'ik Eskimo. However, I appreciate that not all informants will agree with all of the findings. Congruent with the Culture Care Theory, diversity of findings is expected and respected. I confirmed with informants what is generally accepted as true and accurate. At the close of data analysis findings were shared with several key and general informants to confirm study findings. Systematic data collection, analysis, and documentation increases the propensity for traceable data back to the original sources.

Meaning-in-context. Leininger (1990, 2006b) defines meaning-in-context as "relevancy in situ" (1990, p.43) and refers to "data that is understandable and relevant within certain situations, settings, and life experiences" (Leininger, 1990, p.43). Context

relevant to this study is the culture care expressions, meanings, patterns, practices related to end-of-life for Yup'ik Eskimo. End-of-life meanings for Yup'ik Eskimo requires discovery in the cultural setting. Multiple methods of data collection and data collection strategies are critical to ensure meaning-in-context. This study used observation, participation, and interviews. Through a rich, detailed, and true representation of the domain of inquiry the meaning-in-context is appreciated by the key informants and the general informants as a recognizable meaningful representation of the patterns, beliefs, and practices of Yup'ik Eskimo end-of-life care. Through the "repeated direct and documented evidence" (p.77) established through member checks meanings-in-context are confirmed.

Recurrent patterning. Defined by Leininger (1990, 2006b), recurrent patterning refers to the experiences and meanings that occur over time. Consistency in patterns can be anticipated and identified through prolonged engagement. Immersion in the Yup'ik Eskimo culture allowed for an opportunity to appreciate similarities and differences inherent to end-of-life care between Yup'ik Eskimo (emic) and non-Yup'ik Eskimo (etic). Recurrent patterning was identified and related back to the meaning-in-context regarding end-of-life care as known and understood by Yup'ik Eskimo over time.

Saturation. Data collection continued until evidence of redundancy. According to Leininger (1990), redundancy refers to the similar and repeated "ideas, meanings, and descriptions" (p.43) among the informants. Only when a thorough exploration of the domain of inquiry for this study was obtained was the data deemed as saturated

(Leininger, 2006b). This was accomplished by swift journaling of observations and interviews followed by initial analysis. Initial interpretations were directed by the domain of inquiry and the research questions while remaining open and aware of new discovery. Redundancy of data leading to saturation was confirmed by expert mentor and key informant assistance.

Transferability. Finally, despite the criterion of rigor for qualitative research, transferability of findings it was not a goal of this study. Similarities, not identical findings, may be appreciated among end-of-life care in other cultural contexts. Nurses may integrate findings from this study into future ethnonursing discovery about end-of-life care in other cultures remembering that an assumption of transferability among or between cultures potentiates bias and stereotyping.

Research mentors are essential to the ethnonursing research process (Leininger, 2006b). I was privileged to have several research mentors assist me during all phases of the study development, implementation, and analysis. Three mentors are certified transcultural nursing experts. Two mentors have qualitative research expertise and one has anthropological expertise. Leininger notes mentors assist to (a) reduce biases, (b) ensure grounded interpretations, (c) spark reflection leading to meaningful connections among diverse and universal findings, and (d) assist in processing the amassed data which at times can be overwhelming.

Chapter Summary

This chapter has addressed the method and design chosen to discover the end-of-life culture care expressions, meanings, patterns, and practices among Yup'ik Eskimo. The use of the ethnonursing research method enablers assisted with entry to the field, provided for guided reflection, and lead to authentic and credible study findings. The process by which informants were obtained, data was analyzed, and the criteria for qualitative evaluation were explicated. The ethnonursing research method is well suited for the purpose and goal of this study.

Chapter 4

Findings

This ethnonursing study describes the end-of-life culture care expressions, meanings, patterns, and practices among Yup'ik Eskimo and presents discoveries of Yup'ik Eskimo worldview and social structure dimensions within the context of end-of-life care. The major themes identified are presented and supported by the predominant patterns and descriptors extracted from the raw data. Themes two and three explore universalities and diversities which is congruent with the Culture Care Theory (CCT). According to CCT it is equally important to discover what is and what is not culturally congruent care. Finally, the culture care theory action and decision modes which demonstrate the integration of the research findings into nursing practice are provided.

Ethnodemographics

Informants (n = 23) in this study were obtained in Bethel, Alaska and Anchorage, Alaska. Both cities are small and specific information could make for easy identification of individual informants. Demographic information reported here is minimal in an effort to maintain maximum anonymity. The key informants (n = 10) in this study were females (n = 6) and males (n = 4), mean age of 57.2 years of age, who identify as Yup'ik Eskimo, and who were interested in sharing their knowledge of end-of-life culture care expressions, meanings, patterns, and practices inherent in their lifeways. General informants (n = 13) were females (n = 8) and males (n = 5), mean age 54.5 years of age, who did not self identify as a Yup'ik Eskimo, but who were engaged with the Yup'ik

Eskimo culture. These persons practice with or among or serve the Yup'ik Eskimo community.

Ethnohistory

Informants described that no "formal" roads connect Bethel to any major cities in Alaska or to the surrounding villages. Travel to Anchorage is only achievable by air. Informants shared that "two jets" fly in and out daily. Informants added that smaller planes fly in and out but there are numerous stops which turn the one hour trip into multiple hours. The weather has a huge impact on air travel. Informants described instances where fog, snow, or high winds will "weather planes in or out".

In the summer months travel from village to village is accomplished through boat travel on the Kuskokwim River, by three or four wheeler all terrain vehicles, or on foot. In the winter months the frozen Kuskokwim River "road" becomes a conduit for travel between villages by snow machine or automobile. Additionally, the frozen tundra allows for snow machine travel between villages.

The informants in this study shared that healthcare is the leading industry and employer in Bethel. There are forty-one clinics in the Y-K Delta servicing the fifty-six villages. Clinics are staffed primarily by community health aides and may also include a nurse practitioner, physician assistant, or physician. Additional treatment or services are available at the regional health care facility in Bethel, which requires air transport. The average cost of a round trip ticket between villages and Bethel is $100.00. Should persons require advanced medical treatment; travel between Bethel and Anchorage

requires air transport. The average cost of a round trip ticket from Bethel to Anchorage is $500.00. For persons requiring medical care beyond the services provided in Bethel only the patient and one escort are provided transportation free of charge. Informants shared that "this is a *huge* hardship … family cannot afford to go to Anchorage for long term or often to visit … a person can end up dying alone away from family or away from the Delta".

At the time of this study there is no long term care facility in Bethel, there is no out of hospital palliative care or hospice service available, and there is not an assisted living facility. Currently, persons with chronic illness or end-of-life care needs requiring out of hospital professional care (i.e. assisted living or hospice care) do not have resources available to them in their home or home community. These services are currently only available 500 miles away in Anchorage, Alaska. This means that for many of Bethel, Alaska's Yup'ik Eskimo residents end-of-life care takes them away from their family, their community, and their own home. Yup'ik Eskimo persons described this as end-of-life culture care that is not culturally congruent with their expressions, meanings, patterns, and practices.

Yup'ik Eskimo Worldview and Cultural Values, Beliefs, and Lifeways

Yup'ik Eskimo culture care expressions, meanings, patterns, and practices are in all ways and in all manners always cognizant of what lies ahead. Life is described as cyclical and death is not final; spirits are born into future generations. A key informant described "the Yup'ik Eskimo name [child naming practice] continues the person". This

belief “extends to all creatures” a general informant explained. The informant continued to describe the reverence that Yup’ik Eskimo pays to animals hunted and eaten, “all parts are used or eaten and what isn’t [sic] is carefully disposed of – the beaver is returned to the stream so it can live again and allow itself to be caught again” … “We have much to learn from this perspective”.

Family and community are the foundation of Yup’ik Eskimo worldview. This outlook is best summarized by one informant, *“family is where our world begins”*. Key and general informants shared that family and community are synonymous in Yup’ik Eskimo culture. What follows is a discussion of end-of-life culture care expressions, meanings, patterns, and practices among Yup’ik Eskimo.

Cultural and Social Structure Dimensions

The remaining CCT social and structure dimensions considered important in this study and not previously addressed in the ethnodemographics or ethnohistory are described below. The CCT sunrise enabler cultural and social structure dimensions are separated out by headings for the convenience of the reader. However, it is important to note the theoretical Yup’ik Eskimo perspective is that each dimension overlaps and influences the other.

Kinship and social factors. A respectful greeting between persons establishes familiarity. In observations it was noted that the first question asked was “who is your family” or “do you know …”? Gatekeepers reinforced that names are important to remember. It is a show of respect to greet persons by name after learning a person’s

name. When connections are made conversations easily unfold from this common bond. This adage was described most often in the context of relationships between Yup'ik Eskimo and non-Yup'ik Eskimo. When respectful common bonds are not established relationships do not develop. A general informant shared this example, "kass'ag [white people] come out here [village name] 'national geographic' taking pictures to post [website name] without getting to know people or asking people first".

Elders are considered, as one informant shared, "the oak tree that holds the family together". However, being elderly does not constitute being an elder. Many key informants shared in similar adages, "a leader is identified by the wisdom of actions, not by being the person who speaks first, speaks the loudest or longest". Key and general informants confirmed the review of literature findings presented in chapter two. It is understood that the elders hold much of what is left of traditional Yup'ik Eskimo culture and Yup'ik Eskimo language. In addition it was observed in gatherings that when an elder spoke all others respectfully listened, seats were relinquished to elders when no seats where available, plates of food were served to elders, and when an elder entered a room all others greeted the elder.

Childrearing is the responsibility of the family and community. Key and general informants commented "discipline being everyone's business", with several adding that "technology is changing this" creating "social boundaries of action". When asked to explain this more clearly, one key informant described a time when any parent could correct a child's action and not be questioned by the child's parent. Today, the

informant continued, “[some] parents tell me not to correct the child, they are the parent”.

Cultural identity, as taught intergenerationally, and discipline is a strong observable presence in Yup’ik Eskimo culture. Yup’ik names are given to children when they are born. This act emphasizes veneration and preserves the identity of the person deceased. Respect for elders and the consequences of disrespect were observed on many occasions. When addressing a child to be disciplined elders, adults, and parents alike do not make eye contact with the person being scolded. Their gaze is directed down so as not to make direct eye contact. Several key informants shared that this is a common “scolding or ostracizing form of discipline”. The reverence for elders, preservation of traditional names, and discipline in Yup’ik culture is very conspicuous.

Religious/spiritual and philosophical factors. Russian Orthodox and Roman Catholic are the predominant religions of the Yup’ik Eskimo of the Y-K Delta. Much care has been taken, as one general informant explained, to “bridge traditional practices and religious practices” and to “sew back together traditions”. Two general informants shared that many ceremonies are conducted in Yup’ik Eskimo and hymnals are continuingly being translated to Yup’ik Eskimo language. Key informants shared that blending traditional customs with Christianity is facilitated when both sides are open to each other. Many informants shared that religious services presented in both Yup’ik Eskimo and English have created community cohesion. In addition, key and general

informants shared that Christian religious beliefs and Yup'ik Eskimo traditional beliefs share more commonalities than differences, for example life after death.

A traditional Russian Orthodox Slavic celebration was observed. The Russian Orthodox congregation visits community host homes during this week long celebration held the first week of January. In the period leading up to the Slavic celebration homes maintain open curtains and blinds to be open to the Holy Spirit. The congregation walks from home to home in this celebration of Christ's birth during which each home is blessed for the coming year. The processional is led by the priest and two chosen persons from the congregation. One person carries and maintains a spinning star of Christ and the other carries and holds high a banner depicting the Holy Trinity.

There were approximately 100 persons (men, women, and children of all ages) participating on this cold winter night in Bethel. The temperature that evening was minus 20˚F. Eight homes were visited on this day. Participants met early in the afternoon and the event lasted into the early morning hours of the next day. Each family who hosted the event prepared food and provided gifts to all the attendees. The average size of a home in Bethel is 1250 square feet. Every effort is made to accommodate all of the approximately 100 persons participating in Slavic. Chairs and tables are removed from the main gathering room, children sit of the lap of an adult or older sibling, and every elder is provided a place to sit.

At each home the event consisted of prayers, hymns, feasting, and the passing of gifts and lasted approximately two hours. The prayers and the hymns were spoken and

sung in Yup'ik Eskimo. The foods shared afterward consisted of non-traditional foods and traditional Yup'ik Eskimo foods of fish soup, dried fish and agutuk (Eskimo ice cream made from whale or seal fat, berries, and sugar). The gifts passed to each person in attendance consisted of gloves and socks for men and sewing items and washcloths for women. Children received gifts of candy and toys.

The cyclical worldview of the Yup'ik Eskimo is prominent in after death rituals. Birth and death are infinite and this perspective is reflected in varying Yup'ik Eskimo lifeways (i.e. child naming practices, reverence to all living things). Regarding the Yup'ik Eskimo worldview of life and death a general informant described it as, "a relationship between dead and born", "a cycle of coming back", and "resurrection". All key informants shared that the period of mourning after death is blended between traditional Yup'ik Eskimo and Christianity observances. A common practice is "laying out" of the body after death. The exact time frame for "laying out" is individualized. General and key informants described time frames from one day to three weeks. This period of time is for persons to come and pay their respects. The observance is held in the home and it was shared by one general informant that often persons come and stay for days and weeks, "the person who died is in one room and an adjoining room is filled with persons who came to show respect".

After death there are periodic feasts or "potlatches" for the deceased to which the entire community is welcome. Feasts are a time in which all community members come together to remember the person who died. Informants shared variation in the

feasts which was explained as dependent on the level of organized religious acculturation and village practice. In general, informants noted feasts often occur after the funeral, on birthdays, and holidays. Specific patterns for feasting after a person's death were at twenty days, forty days, and one year. One key informant also shared that there is a four year feast which marks a woman's formal availability to remarry.

Major Themes of Yup'ik Eskimo End-of-Life Culture Care

Three major end-of-life culture care themes among the informants were identified as similar in the context of community settings. The themes were derived from expressions, meanings, patterns, and practices of end-of-life care as described by the Yup'ik Eskimo and non-Yup'ik Eskimo informants in the interviews, participant experiences, and field note journal observations. The following three themes supported by the recurrent care patterns and key and general informant descriptors are (a) care is *uptete* (to get ready to go), (b) care is *ilakellriit* (community and family), and (c) professional care is *to do*.

Theme One - Care is *Uptete*: To Get Ready To Go

From the recurrent descriptors and derived descriptive patterns the theme of care is *uptete* (to get ready to go) was discovered embedded in the expressions, meanings, patterns, and practices of Yup'ik Eskimo informants. Key and general informants shared common adages referring to all of one's current life as preparing for the next life. The following patterns derived from recurrent descriptors among the key and general informant interviews and participant observational experiences are:

1. Yup'ik Eskimo end-of-life care is rooted in the belief that one's current life is in preparation for the next life.
2. Yup'ik Eskimo end-of-life care incorporates the belief that life is cyclical.
3. Yup'ik Eskimo end-of-life care is reflective of generational intraconnectedness among past, present, and future peoples.
4. Yup'ik Eskimo end-of-life care is reflected in preserving ancestors through traditional naming practices.

The recurrent care pattern, *Yup'ik Eskimo end-of-life care is rooted in the belief that one's current life is in preparation for the next life*, is evident in the following descriptors extracted from the raw data. During the initial visit to Bethel scheduled interviews were cancelled because of the plentiful ripe low bush blueberries and blackberries and an abundant run of salmon in the river. General and key informants communicated that winters are cold and long and a well stocked freezer is a necessity for survival, therefore these activities become priorities.

General and key informants shared stories at informal or community gatherings and in individual interviews which described getting ready at end-of-life as a process which includes (a) "teaching", (b) "cleaning up", (c) "getting dressed", and (d) "departing". One key informant shared that getting ready at end-of-life for Yup'ik Eskimo is about teaching, "sharing important wisdoms or teachings with children or other family members". Cleaning up at end-of-life was explained as "forgiving", "unburdening" one self from emotions in an effort to "protect yourself". Emotions and

feelings were described as something that could “cause a person to get stuck” between worlds. It is therefore important that persons relinquish any “heaviness” that might weigh them down in this world.

For Yup’ik Eskimo at end-of-life “getting dressed” refers to preparations. Many general informants shared that this process of “getting ready to go” can be equated to the Western end-of-life process of “getting affairs in order”. The time period of “laying out”, what clothes, foods, and after death rituals that will be observed are discussed and are all a part of “getting dressed”. Key informants shared that some younger persons today follow instructions given as a show of respect even though they often do not understand what they are doing or why they are doing it. One key informant shared a specific example of two girls who were instructed by their auntie to wear a string around their waist and to wear a hat for one year after their mother’s death. The informants were unclear as to why they had to participate in this after death ritual but commented that every time the string wedged itself uncomfortably they thought of their mother or when they were bathing they thought of their mother. The key informant shared that departures are hard and remembering eases the pain. For many Yup’ik Eskimo bathing is accomplished by *steaming.* Public water or wells are not a part of many villages. Small wooden structures house a central fire pit where rocks are assembled. Water from streams or rivers is poured over the rocks to create the steam.

The second and third recurrent care patterns which supported theme one, *Yup’ik Eskimo end-of-life care incorporates the belief that life is cyclical* and *Yup’ik Eskimo end-*

of-life care is reflective of generational intraconnectedness among past, present, and future peoples, became evident from the descriptors in the raw data. All general and key informants shared that the connectedness between the past, present, and future is inseparable. One key informant emphasized that "the past is not a burden - it brought me to this path" and "death is part of life – it is accepted, my past is part of that path and in dying I become the future". Another key informant shared "we are always looking ahead" … "our ancestors are built into our bodies – they are our bone marrow, our parents are our bones, and the flesh is who we are now".

The fourth recurrent care pattern which supports this theme, *Yup'ik Eskimo end-of-life care is reflected in preserving ancestors through traditional naming practices*, was identified in the informant's descriptors. Children are given the Yup'ik Eskimo name of the deceased and gender is not relevant when naming. Informants explained that the child personifies the name of the deceased. It was observed on various occasions that children would be referred to as father, mother, auntie, or brother regardless of age or gender. Key informants shared that this practice continues the circle. One key informant noted that "we are not ourselves; we are our ancestors, our children, our earth, our universe". Similarly another key informant added "ancestors are built into our body systems; we are our ancestors we are not separate".

To summarize, end-of-life culture care expressions, meanings, patterns, and practices for Yup'ik Eskimo universally attend to *uptete* (to get ready to go). Key and general informants all described specific patterns of getting ready to go or practices

which supported getting ready to go and maintaining the cyclical intraconnectedness of generations.

Theme 2 - Care is *Ilakellriit:* Community as Family

Theme two, care is *ilakellriit* (community as family) was discovered in the informants descriptors and recurrent care patterns embedded in the end-of-life culture care expressions, meanings, patterns, and practices. This theme is advanced by three universal recurrent care patterns and two diverse recurrent non-care patterns which were derived from the descriptors among the all key and general informant interviews and participant observation experiences. The recurrent patterns are:

1. Yup'ik Eskimo end-of-life care is grounded in the belief that community is family.
2. Yup'ik Eskimo end-of-life care is preferred in the home or the home community context.
3. Yup'ik Eskimo end-of-life care acknowledges the responsibility of the family and the community as integral facilitators in end-of-life care processes.

The two diverse recurrent care patterns were:

1. Care received away from the home community
2. Care in artificial communities (healthcare facilities away from home and community)

The first and second recurrent care patterns, *Yup'ik Eskimo end-of-life care is grounded in the belief that community is family* and *Yup'ik Eskimo end-of-life care is preferred in the home or the home community context,* became evident in the raw data

descriptors provided by key and general informants in informal gatherings and individual interviews. During an initial exploratory visit to Bethel it was observed that gatherings (i.e. marriages, birthday parties, feasts) are open to everyone. It was discovered that one person invited to an event will come to the event with several other persons. It was observed during community events or gatherings that introductions stressed making connections between families or villages. One key informant noted "when we hear someone is from [village name] we ask, do you know this person or that person – it brings us close together". Another key informant added "gatherings are great ways to reconnect with people you don't [sic] see often" and "when we come together we make a village where we are".

At end-of-life the importance of community and family was described by one general informant as "families who care for their loved ones despite no assistance – it is a responsibility". The general informant continued noting that "family is an interesting word here [village name] – everybody is family". It was discovered that blood relationships alone does not constitute family, community constitutes family. A key informant clarified this finding by adding "our survival has always required family and community".

The third recurrent care pattern which supports the theme that became evident in the key and general informants descriptors was *Yup'ik Eskimo end-of-life care acknowledges the responsibility of the family and the community as integral facilitators in end-of-life care processes*. One key informant recalled "as a child many people came

after my mother died [and] they took care of me and my brothers, they took care of the house" … "now I go when there is a death, I leave work and I travel up the river and stay for as long as I am needed – it is what we must do to survive". Another key informant clarified this further, adding "yagluteng – Yup'ik Eskimo word that means taking care of the family and family responsibilities to allow the family to grieve".

Evident in the raw data descriptors of theme two was diversity in the theme. The recurrent non-caring care patterns which became evident in the expressions, meanings, patterns, and practices of general and key informants were described as *care received away from the home community* and *care in artificial communities (healthcare facilities away from home and community)*. One key informant noted that "families go to great lengths to learn how to care for a family member in order to ensure they can stay at home" and added "I have seen persons suffering great pain, families who have loved ones who are in pain and let them alone because they know their loved one would rather be in pain then far away in a hospital".

A key informant stated "many times I have heard how there are no choices in [hospital name]" and "the threat of unwanted medical services looms". Another key informant described how "there are no traditional foods" and "I need to see the landscape I have known for an entire life". The informant further clarified by adding "everything and everyone is part of that landscape". A general informant contributed to this by stating that "hospitals are full of archaic rules like 'no one under 13 allowed' – really – dying people don't [sic] know any children"? Another general informant added

"I believe end-of-life care is currently designed to meet medical standards of care and it has little or nothing to do with patient quality."

To summarize, end-of-life culture care expressions, meanings, patterns, and practices which describe care as *ilakellriit* (community as family) were provided through universal and diverse key and general informant descriptors. Key and general informants described specific patterns of care practices and non-care patterns which supported the theme.

Theme 3 – Professional Care is *To Do*

The final theme, professional care is *to do,* was discovered embedded in the informant descriptors of end-of-life culture care expressions, meanings, patterns, and practices. Theme three was extrapolated by the following two universal and one diverse recurrent care patterns which were derived from the descriptors among the key and general informant interviews and participant observation experiences. The recurrent universal patterns are:

1. Professional care for Yup'ik Eskimo at end-of-life emphasizes action over words.
2. Professional care for Yup'ik Eskimo at end-of-life is an *allowing presence*.

The recurrent diverse pattern is:

1. Non-caring for Yup'ik Eskimo at end-of-life is *uqamaite* (to be heavy).

The first care pattern, professional care for *Yup'ik Eskimo at end-of-life emphasizes action over words*, was described by one key informant as "don't [sic] try – do". This adage was confirmed and clarified with other key and general informants.

One key informant reflected on the care of a family member away from Bethel, “a nurse or a doctor does not have know all or be all – but they need to be more than just there”. The key informant clarified this statement by adding “when my mother was ill she [nurse name] didn’t [sic] say much – she was very quiet but her [nursing] care said everything” … “ after the medical care team met, which they always asked me to come to, she [nurse name] checked to make sure I didn’t [sic] have questions”. Many key informants shared similar stories of end-of-life care which described caring actions by healthcare providers which were recalled more than words spoken. Key informants explained this as a central feature of Yup’ik Eskimo culture. Actions are held in higher regard than words. It was emphasized that saying something will be done is less important than seeing something done. Key informants described times when the actions nurse said they would do were not carried out; this is what was remembered, the intention to do is less important than the action of doing.

The second recurrent care pattern *professional care for Yup’ik Eskimo at end-of-life is an ‘allowing presence’* supports theme three as evident in the key and general informant descriptors provided here. All key informants described death as part of life, as a “journey”, a “passage”, “the path to becoming”. An *allowing presence* by healthcare providers is one which does not interfere with the journey, passage, or the path to becoming. One key informant clarified this by stating that “allowing is not permissive; we do not need permission, we need someone who is open”. A key informant described this as “persons dying have heightened senses – they are alert to

smells, sights, and people – they can feel people – nurses need to know this". Another key informant clarified this with a description about a family member's end-of-life care in the hospital.

> … he was very weak, he didn't [sic] move hardly at all – then one day I come to find him standing next to the bed with fear in his eyes – he said that [name of person] was coming to see him and he did not want to see him – 'don't' [sic] let him in' he said to me – a nurse came in and tried to get him back in bed but he would not go then another nurse came and spoke to him in Yup'ik - he let them get him to bed.

The informant explained that the first nurse must have "carried with her" a "heaviness" that the family member could sense and that interfered with the care the nurse was trying to provide. The second nurse, who was Yup'ik Eskimo, must have known of this Yup'ik Eskimo sensitivity at end-of-life and was able to provide care.

This theme is more clearly understood by the diversity described in the third recurrent care pattern, *non-caring for Yup'ik Eskimo at end-of-life is uqamaite (to be heavy)*. All key informants spoke time and again about dying as part of a "path to becoming" and how persons can get "stuck in between" life and death. Key informants described how healthcare provider's emotions can bring "heaviness" to end-of-life care for Yup'ik Eskimo. When asked for a clearer description, one key informant explained,

> I know nurses have things that they bring with them to work, maybe they had a hard time getting the kids to school, the car would not start, or

> they heard bad news. But when you [nurses] care for a Yup'ik Eskimo person who is dying they sense that and it burdens them.

Another key informant added "nurses need to listen to know and ask to know, listen to hear … trying to be perfect, being in a hurry, or trying to please everyone makes care cold and unfeeling". Several key informants added that "heaviness is heavy words too". All key informants stated time and again that Yup'ik Eskimo acknowledges death – they acknowledge death "gently". One key informant stated "we use gentle words – let me tell them they are dying". Another key informant added "doctors and nurses just say 'we tried everything' or 'there is nothing we can do' – then they start asking about restarting his heart if it stops". Key informants noted that heaviness can "break the spirit". One key informant described this as giving up the will to live. Another key informant described an instance where an elder seemed to have willed themselves to die after being told of the terminal nature of their illness.

A general informant described feeling "… at a loss not knowing what they [Yup'ik Eskimo persons] want, *really* want". Another general informant clarified this by stating "I am a good nurse, I know my job, but not knowing sometimes what a person wants is frustrating – I will just sit and that seems to make people [Yup'ik Eskimo] happy or put them at ease but I just feel like there is more, like I am missing something very important". This sense of frustration was described often by general informants involved in direct patient care. Key informant data concerning heaviness was discussed with the general informants for confirmation and clarification and it was discovered that

many had not considered the weight they might carry into a care interaction. One general informant noted “can it really be that simple, how did I not know this – really?” Another general informant added:

> you know now that you mention this I had a patient family member ask me once ‘you look worried’ – I didn’t [sic] think anything about it but she must have sensed what was on my mind – I responded that I was fine and went about with checking pumps [intravenous], the vent [ventilator] – she didn’t speak to me much the rest of that shift – my actions obviously spoke louder than my words and I thought my actions showed great professional care.

Discord between Western healthcare providers and Yup’ik Eskimo healers was discovered in the key and general informant’s recurrent care pattern descriptors which support theme three. Several key informants described themselves as traditional healers but added “we are underground”. When asked to clarify the key informant stated “not many white people are accepting of our traditional ways – remember when the missionaries first came here they told us that it [traditional healing] was of the devil – so many stopped speaking of it or stopped practicing it for fear”. Key informants shared that they will visit when asked by family but they do not identify themselves to healthcare providers as being a healer. A key informant noted “I bring peace and healing – I know I won’t [sic] make someone well if they are dying – I cure the soul”.

The majority of the general informants had heard about or knew of traditional healers in the Yup'ik Eskimo community. One general informant stated that "healers have come to visit, at first I didn't [sic] know who they were – but I did notice a change sometimes in my patient – they were calmer or at ease". Another added that "sometimes someone will mention 'we should suggest a healer visit' seems to me it should be the patient asking – I don't [sic] know." All general informants agreed that traditional healers should be a part of end-of-life care for Yup'ik Eskimo persons, "there's [sic] a lot of value in adding patient preferences – end-of-life care should be about what the patient wants".

In summary, professional end-of-life care for Yup'ik Eskimo was shared in the key and general informant descriptions of what is and what is not culturally congruent end-of-life care for Yup'ik Eskimo. End-of-life culture care expressions, meanings, patterns, and practices which describe professional care as *to do* were provided through universal and diverse key and general informant descriptors. Key and general informants described specific patterns of care practices and perceived non-care practices which positively or negatively affects end-of-life care for Yup'ik Eskimo.

Discoveries for Professional Yup'ik Eskimo End-of-Life Care

Culture care theory research discoveries guide nursing practice using the three predicted modes of nursing action and decisions (a) culture care preservation/maintenance, (b) culture care accommodation/negotiation, and (c) culture care repatterning/restructuring (Leininger, 2006a). The modes discussed here were

abstracted from the recurrent care patterns and themes discovered in the key and general informant's expressions, meanings, patterns, and practices as part of participant observations, described in individual interviews, and as confirmed by informants. The care modes support Yup'ik Eskimo end-of-life culture care by assisting nurses in making decisions and in formulating actions which are culturally congruent.

Culture Care Preservation/Maintenance

Significant findings in this study indicated that key and general informants emphasize community and family are inseparable and community and family have specific end-of-life care responsibilities. The end-of-life care practices which are important to preserve or maintain are those which emphasize community as family.

1. It is important to preserve and maintain the community as family perspective and to acknowledge community has equal value as family for Yup'ik Eskimo.
2. Honoring and respecting Yup'ik Eskimo intragenerational connectedness must extend from immediate family members to community members to preserve and maintain optimal family and community involvement.

Culture Care Accommodation/Negotiation

A significant finding in this study *uptete* (to get ready to go) was discovered embedded in the Yup'ik Eskimo end-of-life culture care expressions, meanings, patterns, and practices. Nurses must accommodate/negotiate Yup'ik Eskimo end-of-life preparations and rituals, traditional foods, and generic/folk care. The following end-of-life care practices should be accommodated or negotiated for Yup'ik Eskimo.

1. Large gatherings and the use of traditional foods is important for Yup'ik Eskimo at end-of-life. The preferred use of traditional foods should be accommodated when this practice is not contraindicated to the plan of care.
2. The aftercare ritual of "laying out" is especially important when end-of-life occurs away from the home and home community. The "laying out" period after death for Yup'ik Eskimo provides a time for persons to come and pay their respects. In the home and home community context this period can last days or weeks.
3. Key and general informants acknowledged the importance of the traditional healer for Yup'ik at end-of-life care. For Yup'ik Eskimo traditional healers can "cure the soul".

Culture Care Repatterning/Restructuring

Significant findings in this study indicate that nurses unconsciously carry personal emotions which are intrusive to Yup'ik Eskimo at end-of-life. In addition, nurses need to be active participants in the development of culturally congruent hospital and community based end-of-life care services needed to maintain individuals in the community setting at end-of-life. The nurse actions and decisions to repattern or restructure Yup'ik Eskimo end-of-life care are to:

1. Recognize, repattern and restructure patterns of "heavy" behaviors when caring for Yup'ik Eskimo at end-of-life.

2. Restructure end-of-life care which honors Yup'ik Eskimo desire to be in the home community setting and cared for by the family and community.

Chapter Summary

This chapter presented the findings of the study. Included were the informant ethnodemographics and the Yup'ik Eskimo ethnohistory, worldview, and social structure dimensions discovered within the context of end-of-life care for Yup'ik Eskimo. Major themes supported by the predominant patterns and descriptors were extrapolated. The culture care theory action and decision modes demonstrated the integration of research findings into nursing practice and provided support for the development of culturally congruent palliative and end-of-life care programs for Yup'ik Eskimo.

Chapter 5

Discussion of Findings

The purpose of this study was to discover end-of-life culture care expressions, meanings, patterns, and practices among Yup'ik Eskimo. In this chapter study findings that support the theoretical assumptive premises are presented. Established care constructs were further substantiated by study findings. The identification of new care constructs contributes to the body of transcultural knowledge. Findings are compared to previous ethnonursing and end-of-life studies. The implications for nursing practice, and education, and policy are discussed and recommendations for future research are presented. Finally, the researcher provides personal reflections on the study which may be useful to others who study end-of-life care among diverse cultures and specifically Yup'ik Eskimo.

Contribution to Nursing Theory

The CCT theoretical assumptions which guided this research study in the discovery of culture care expressions, meanings, patterns, and practices related to end-of-life care among Yup'ik Eskimo in community settings are revisited here. Previously known care constructs are supported by this study and two new care constructs were discovered. Nurses use this knowledge to provide culturally congruent care.

Assumptive Premises

The first assumptive premise of this study, care is essential to Yup'ik Eskimo at end-of-life is supported by the discovery of theme two (*care as ilakellriit [community as*

family]) and in the caring and non-caring patterns of theme three, *professional care is to do*. For Yup'ik Eskimo community and family are essential for their end-of-life care. Key informants provided rich descriptors of efforts made by family members to provide care, despite lack of formal care or assistance, in order to maintain a dying family member in the home or home community. Key informants also described travelling to homes to assist with care. Furthermore, descriptors provided by key informants detailed unspoken responsibilities of community members which served to lessen the burdens of everyday task so that family members were free to grieve.

An equally important discovery which supports this assumptive premise is the effect of professional non-care as described by the key informants in this study. Many general informants described not knowing what their personal emotions or problems bring to the end-of-life experience for Yup'ik Eskimo. In addition, Yup'ik Eskimo at end-of-life value actions over words. For general informants providing direct patient care this was not overtly known and was often the cause of frustration.

The second assumptive premise of this study, end-of-life culture care expressions, meanings, patterns, and practices for Yup'ik Eskimo are influenced by and embedded in worldview, cultural and social structure dimensions is supported by theme one (*care is uptete [to get ready to go]*). Key informants described in detail what it means to get ready to go. Examples of the worldview and social structure dimensions inherent in getting ready to go were imparting or sharing wisdoms, forgiving, final preparations and after death observances (i.e. laying out and feasts). Child naming

practices discovered in the descriptors of the key and general informants is illustrative of the cyclical worldview of Yup'ik Eskimo and reinforces the strongly held lifeway of generational intraconnectedness.

The caring and non-caring recurrent care patterns of theme three, *professional care is to do*, support the third assumptive premise that every culture has generic (lay, folk, naturalistic; mainly *emic*) and usually some professional (*etic*) end-of-life care to be discovered and used for culturally congruent practices. Leininger's three theoretical modes of care provided for the identification of new, creative, and different therapeutic ways to help Yup'ik Eskimo with end-of-life care which supported the fourth assumptive premise of the study. The study findings support exploration of community and family centered care practices, provision of traditional foods, acceptance of traditional healers, and the establishment of culturally congruent palliative care and community based hospice care. All four assumptive premises of this study, derived from the culture care theory theoretical assumptions, were supported and therefore further substantiate the CCT.

Care Constructs

Care constructs reveal the roots of universal and diverse culture care knowledge inherent to a people. To date there are 175 care constructs identified from among 58 cultures (Leininger, 2006c). The care construct previously identified by Leininger and others which was abstracted from the themes and recurrent patterns discovered in this study is *family involvement*. Three new care constructs discovered embedded in Yup'ik

Eskimo end-of-life culture care expressions, meanings, patterns, and practices are *preparation*, *community as family*, and *presence*. While there is an existing construct named presence (being with), it needs to be differentiated from the construct emerging from this study wherein presence equates with allowing.

Family involvement. In Yup'ik Eskimo culture family involvement at end-of-life was described through numerous examples. Family involvement consisted of caring for persons at end-of-life despite minimal formal caregiver assistance; it is a responsibility, and a great dishonor to delegate care. At end-of-life and after death Yup'ik Eskimo described travelling to neighboring villages and staying as long as was needed to assist others. In addition, Yup'ik Eskimo spoke about family involvement when telling of death and dying. Words can "break the spirit"; Yup'ik Eskimo prefer to tell of death in their own words and in their own way.

Holt (2001), in her study of end-of-life customs among Eritrean, described the care construct of family involvement as a unifying force which maintains family ties. Eritrean's emphasis on family involvement at end-of-life underscored a sense of obligation and was described as "the core of someone's existence" (p. 152). In addition, Holt added that in Eritrean culture it is the duty of the most responsible person to divulge news of worsening illness or death. Bonura et al. (2001) in their study of culturally congruent end-of-life care among Jewish patient and families found that family involvement was considered a (religious) responsibility and often involved spending great lengths of time caring for family members. Family involvement for

Jewish persons at end-of-life is attentive end-of-life care which demonstrates the value of life.

Similarly, Gates (1988) in a qualitative study to learn the meanings and experiences of care and cure among dying patients in hospital and hospice settings using CCT found that patients preferred family involvement in care over care provided by professional healthcare staff. Family involvement was highly valued in both settings. Informants in Gates' study described care at end-of-life provided by nurses in hospitals in terms of actions or assistance with physical needs (i.e. pain control measures, dressing changes, and incontinence care). Hospital informants valued skill expertise of professional hospital care whereas hospice informants valued personal care.

These studies exemplify diversity in family involvement among and within cultures. It is important for nurses to explore what family and community contextually means for their patients in order to incorporate culturally congruent family involvement at end-of-life.

Community as family. In this study, community as family is presented as a new care construct. Community as family is differentiated from the established care construct community awareness. Yup'ik Eskimo end-of-life culture care goes beyond the community being aware it incorporates unconditional doing for others. In Yup'ik Eskimo culture there is no delineation between family and community. Celebrations, community fairs or events, and end-of-life potlatches are opportunities to be together and to share both resources and strength. Yup'ik Eskimo practice obligations and duties

without words. The responsibilities of family members of the deceased are divided and managed among community members, leaving the family opportunity to grieve. As previously stated, Yup'ik Eskimo persons will travel great distances between villages and stay for as long as they are needed to assist with end-of-life care or duties after death. Community as family for Yup'ik Eskimo is exemplified in the belief that wherever they are, they are a village, they are a community. This new care construct together with the aforementioned action/decision modes provides professional caregivers the knowledge and insight necessary to provide culturally congruent end-of-life care for Yup'ik Eskimo.

Preparation. A second newly discovered care construct embedded in the Yup'ik Eskimo end-of-life culture care expressions, meanings, patterns, and practices was preparation related to getting reading to go. This care construct is unique and no other care constructs could be identified which completely captured the essence of what preparation means for Yup'ik Eskimo at end-of-life. For Yup'ik Eskimo end-of-life culture care is rooted in the belief that one's current life is in preparation for the next life. Preparation involves distinct matters that must be attended to prior to dying. This new care construct combines with action/decision modes to provide professional caregivers insight into the meaning of end-of-life care for Yup'ik Eskimo thus leading to culturally congruent care. While similar in meaning as the Western adage of getting ones affairs in order, attention must be given to the Yup'ik Eskimo interpretation of this phenomenon in order that it might be identified and accommodated by professional care givers.

Presence: allowing. The final newly identified care construct presented is distinct from the established care construct, presence as being with. For Yup'ik Eskimo at end-of-life it was discovered that nurses may bring with them accumulated emotions perceived as heaviness to care interactions. It is important for professional care providers to know the effects of their presence. An allowing presence by professional care givers is not a permissive presence, it is a facilitating presence; a conscious presence. It was a discovered belief that Yup'ik Eskimo persons at end-of-life can get stuck between two worlds by intangibles accumulated by them or brought to them by others. For Yup'ik Eskimo at end-of-life it was discovered that Yup'ik Eskimo do not expect professional caregivers to know everything about their culture, to be able to do everything for them – however they do expect professional caregivers to do more than just be present.

This study further supports and develops the culture care theory through substantiation of four CCT assumptive premises, one established care construct, and the discovery of three new care constructs. Discovery of these new care contrasts assists nurses in understanding culturally congruent care for Yup'ik Eskimo at end-of-life and provides innovative insight into universal epistemic roots of care.

Implications for Nursing Practice

This study contributes to nursing practice by providing previously undiscovered end-of-life culture care expressions, meanings, patterns, and practices among Yup'ik Eskimo. The findings of this study have noteworthy implications for nursing practice.

Practicing nurses may use study findings in their respective fields to provide insight for consideration for the multi-culturally diverse peoples in their care.

Nurses need to know and understand that Yup'ik Eskimo value community as family at end-of-life. Actions and decisions which support the community as family perspective are essential to Yup'ik Eskimo end-of-life care. Nurses need to know this when care conversations include persons who are not blood relatives but who are considered family to the patient. For Yup'ik Eskimo, community has equal value as family. This is supportive of similar study findings (Born et al., 2004; Maddalena, 2009; Quinn et al., 2012) which explored the familial influence at end-of-life across cultures. For Yup'ik Eskimo community is given equal importance as family. Community members may be part of care conversations, decision-making, and desire to be a part of caregiving. This knowledge supports care plans which accommodate the desire for large family gatherings, traditional foods, and family involvement with care.

This study also provides support for similar studies (Baydala et al., 2006; DeCourtney et al., 2010) which emphasized the importance for traditional rituals and collaborative care practices to include traditional healers. Nurses need to support, facilitate, and encourage family and community involvement. This can be accomplished by flexible routines of care that allow for maximum community/family involvement. In addition, nurses must honor and respect Yup'ik Eskimo intragenerational connectedness so that responsibilities are preserved.

Traditional healers were discovered to be an important thread woven into and supportive of the Yup'ik Eskimo cyclical worldview. For Yup'ik Eskimo traditional healers provide emotional healing. Nurses are encouraged to explore the patient's desire for traditional healing in order to accommodate the patients' preference for traditional healing. The nurse can then collaborate and coordinate traditional healing practices into the care plan.

Lastly, nurses must be cognizant of their perceived presence when interacting with the patient and the potential implication on communication patterns. An important discovery in this study was the effect of an emotionally intrusive presence during the end-of-life experience for Yup'ik Eskimo. The nurse must work to recognize, repattern and restructure personal behaviors when caring for Yup'ik Eskimo at end-of-life. Activities which decrease the personal burdens nurses bring to the nurse-patient interaction needs to be explored. Nurses are encouraged to integrate reflective moments into their day which explore the ways in which they can best enter the room of a Yup'ik Eskimo person at end-of-life without displaying their "heaviness".

In support of previous research (Chan & Kayser-Jones, 2005; McGrath &Phillips, 2008; Tulsky, 2005) which uncovered the effect of the nurse's presence at end-of-life nurses need to be mindful that a heavy presence can negatively influence the end-of-life experience for Yup'ik Eskimo. Nurses are encouraged to explore ways in which they might diminish the weighted emotional presence they bring to caregiving interactions. Reflective moments interspersed throughout the day and frank open discussions with

family members away from the patient's bedside are needed for the nurse to appreciate her perceived presence.

Implications for Nursing Education

These findings add to the evolving body of transcultural knowledge. Nursing curricula may include these research findings in efforts to prepare future nurses to care for diverse cultures at end-of-life in a more culturally congruent manner. The classroom and clinical setting is the first best place for students to explore their ethnocentrism. This supports previous works (Crawley, 2005; Hampton et al., 2010; Higginson, 2005) which advocate for the examination of ethical dilemmas, biases, and prejudices.

The themes and care constructs discovered can be integrated into nurse education programs which promote and contribute to the development of culturally congruent end-of-life care for Yup'ik Eskimo. It is important for nurses to know and act on the culture specific practices for the people they serve. Specific culture care content in nursing curricula helps to prepare students to function as proactive participants in the development of culturally congruent hospital and community based care.

This study further supports study findings which explored the contextual experiences at end-of-life (Jenkins et al., 2005; McGrath & Phillips, 2008; Porock, Pollock & Jurgens, 2009; Teno et al., 2004). Nurses must be prepared for the environments in which they will interact with patients, families, and communities. The hospital and home environments offer the nurse unique challenges and opportunities to provide meaningful end-of-life care.

Implications for Health Policy

The publication and dissemination of the research findings will provide healthcare professionals with knowledge about the end-of-life culture care among Yup'ik Eskimo. Findings from this study add to previous works (DeCourtney et al., 2010; Baydala et al., 2006; Hotson, McDonald, & Martin, 2004; McGrath & Phillips, 2008) and may be useful to researchers studying end-of-life among other cultural groups. The acute care services delivered in Alaska have overcome major transportation, weather, and provider resource obstacles. Currently, the acute healthcare needs for persons living in bush Alaska are creatively addressed utilizing community health aids, nurse practitioners, physician assistants, and tele-medicine technologies.

This study has discovered the end-of-life culture care needs for Yup'ik Eskimo living in bush Alaska emphasize remaining in the home and home community. The aftercare ritual of "laying out" is complicated when end-of-life occurs outside the community context. The "laying out" period after death for Yup'ik Eskimo provides a time for persons to come and pay their respects. In the home and home community context this period can last days or weeks.

These findings add to previous work (Kitzes & Berger, 2004) which explored the end-of-life issues for American Indians in Albuquerque, New Mexico. Hospice and palliative care services are complicated for bush dwelling peoples. New information provided here adds to the recommendations by Kitzes and Berger which emphasizes

Tribal networking to effectively address the end-of-life care needs for bush dwelling individuals.

These findings have implications for all Alaskans living in the bush. McGrath and Phillips (2008) identified similar geographic obstacles among Australian Aboriginals which negatively affected end-of-life care and recommended relocation for care at end-of-life as an alternative rather than a routine intervention. The provision of care, the decision-making process, and the available resources in bush locations severely complicates the end-of-life process for the individual, the family, and the community.

This study indicates that the end-of-life needs for Yup'ik Eskimo are not being met to their satisfaction. The findings indicate that choices are limited by the availability of end-of-life care services. Sherry (2004) noted the Alaska Native health system provides a model for sustainability into the future and adds that there needs to be a significant increase in research partnered with and for the Alaskan Natives to improve health and in this instance improve end-of-life care. DeCourtney, Jones, Merriman, Heavener, and Branch (2003) described the obstacles to successful palliative care programs for bush peoples. Much more work is needed to discover innovative ways to address the lack of providers, medication logistics, and geographic obstacles which consistently plagues the delivery of culturally congruent end-of-life care for bush dwelling peoples. This study reveals the need to adapt the current acute care delivery system to include out of hospital palliative and hospice care services for all persons living in bush Alaska.

Recommendations for Future Research

This research study has provided a foundation for anyone wishing to study culturally embedded expressions, meanings, patterns, and practices of end-of-life care. The gatekeepers in this study, together with the key and general informants have all expressed support for this study and its findings, with one key informant commenting "our elders will benefit from your work". All Alaska Natives would benefit from research directed to discover the end-of-life culture care practices of traditional healers. In addition, research directed to discover how traditional healers and Western medical practices can be integrated will support optimal culturally congruent end-of-life culture care for Yup'ik Eskimo. This study revealed discoveries of end-of-life culture care for Yup'ik Eskimo. Future research is needed to discover the end-of-life culture care expressions, meanings, patterns, and practice among other Alaska Native tribes.

Reflections of the Study

This dissertation exemplifies the usefulness of the CCT, the ethnonursing research method enablers, and the ethnonursing research method in revealing deeply embedded culture care expressions, meanings, patterns, and practices. Through participant observation and learning through community participation I learned to listen attentively to the stories told to me by Yup'ik Eskimo and non-Yup'ik Eskimo persons. What I have gathered is but the tip of a very large iceberg. I have much to learn from my newly formed Yup'ik Eskimo relationships. The relationships will assist me in future research endeavors with Yup'ik people as we collaborate to discover how nurses can

meet their culture care needs. I appreciate first and foremost the Yup'ik Eskimo belief that knowledge has always been and is not the sole possession of the individual; the sharing of knowledge must be earned. That is to say, one does not find out because one asks; one is told when one is judged ready to hear, listen, and understand.

Informants shared that in Yup'ik Eskimo worldview, persons who hold knowledge, whether they are an elder or not, will determine when to share their knowledge with others. This adage was communicated to me time and again in participant observations and in individual key and general informant interviews in different ways. For example one general Informant explained this as, "it is about common bonds first", "much is not spoken, (you) must be let in". Similarly, a key informant shared, "watch and the answer to a question will be revealed". My favorite wisdom, shared early in my immersion, "conversations turn to connections" and "trust before revealed" shaped my observational experiences and the interviews by keeping me cognizant of respectful listening and learning.

Conclusion

This study uncovered existing end-of-life culture care expressions, meanings, patterns, and practices among Yup'ik Eskimo. Naturalistic, post-positivist, and participatory world paradigms provided the lens for discovery and the study was conceptualized using the CCT and ethnonursing research method. The assumptive premises of the theory held that end-of-life culture care meanings would be embedded in the worldview and social structure dimensions of Yup'ik Eskimo and as such would

require discovery in the naturalistic community setting. Culture care patterns and themes were extrapolated from the raw data and guided the discussion of culturally congruent action and decision modes of nursing care. This study further supports and substantiates the CCT and contributes to the body of transcultural nursing and end-of–life care knowledge. The study findings are useful to healthcare providers who care for Yup'ik Eskimo at end-of-life.

References

References

Alaska Native Heritage Center Museum. (2008). Culture Map. Alaska's Indigenous People. Retrieved from http://www.alaskanative.net/

Baydala, A., Hampton, M., Kinunwa, L., Kinunwa, G., & Kinunwa, L. (2006). Death, dying, grieving, and end of life care: Understanding personal meanings of Aboriginal friends. *Humanistic Psychologist, 34*, 159-176.

Barker, J. H. (2010). Introduction. In J.H. Barker, A. Fienup-Riordan, & T. A. John (Eds). *Yupiit yuraryarait: Yup'ik Eskimo ways of dancing.* Fairbanks: University of Alaska Press.

Bonura, D., Fender, M., Roesler, M., & Pacquiao, D. F. (2001). Culturally congruent end-of-life care for Jewish patients and their families. *Journal of Transcultural Nursing, 12*, 211-220.

Born, W., Greiner, K. A., Sylvia, E., Butler, J., & Ahluwalia, J. S. (2004). Knowledge, attitudes, and beliefs about end-of-life care among inner-city African Americans and Latinos. *Journal of Palliative Medicine, 7*, 247-256.

Braun, K. L., Pietsch, J. H., & Blanchette, P. L. (2000). An introduction to culture and its influence on end-of-life decision making. In K.L. Braun, J.H. Pietsch, & P.L. Blanchette (Eds.). *Cultural issues in end-of-life decision making.* Thousand Oaks: Sage.

Burch, E. S. (1988). *The Eskimos.* Norman: University of Oklahoma Press.

Chan, J., & Kayser-Jones, J. (2005). The experience of dying for Chinese nursing home residents. *Journal of Gerontological Nursing, 31*(8), (S-1), 26-32.

Chochinov, H. M., & Cann, B. J. (2005). Interventions to enhance spiritual aspects of dying. *Journal of Palliative Medicine, 8,* (S-1), 103-115.

Crawley, L. M. (2005). Racial, cultural, and ethnic factors influencing end-of-life care. *Journal of Palliative Medicine, 8,* (S-1), 58-67.

DeCourtney, C. A., Jones, K., Merriman, M. P., Heavener, N., & Branch, P. K. (2003). Establishing a culturally sensitive palliative care program in rural Alaska Native American Communities. *Journal of Palliative Medicine, 6,* 501-510.

DeCourtney, C. A., Branch, P. K., & Morgan, K. M. (2010). Gathering information to develop palliative care programs for Alaska's Aboriginal peoples. *Journal of Palliative Care, 26*(1), 22-31.

Duffy, S., Jackson, F., Schim, S., Ronis, D., & Fowler, K. (2006). Cultural concepts at the end of life. *Nursing Older People, 18*(8), 10-14.

Fienup-Riordan, A. (1990). *Eskimo essays*. New Brunswick NY: Rutgers University Press.

Fienup-Riordan, A. (2005). *Wise words of the Yup'ik Eskimo people: We talk because we love you.* Lincoln: University of Nebraska Press.

Fienup-Riordan, A. (2007). *Yuungnaqpiallerput: The way we genuinely live.* Seattle: University of Washington Press.

Fortuine, R. (2005). *Must we all die?: Alaska's enduring struggle with tuberculosis*. Fairbanks: University of Alaska Press

Gates, M. F. (1988). *Care and cure meanings, experiences and orientations of persons who are dying in hospital and hospice settings*. Wayne State University, Detroit, Michigan.

Gelfand, D. E., Balcazar, H., Parzuchowski, J., & Lenox, S. (2001). Mexicans and care for the terminally ill: Family, hospice, and the church. *American Journal of Hospice and Palliative Care, 18*, 391-396.

Hampton, M., Baydala, A., Bourassa, C., McKay-McNabb, K., Piacsko, C., Goodwill, K.(2010). Completing the circle: Elders speak about end-of-life care with aboriginal families in Canada. *Journal of Palliative Care, 26*, 6-14.

Hardwig, J. (2009). Going to meet death: The art of dying in the early part of the twenty-first century. *Hastings Center Report, 39,* 37-45.

Hawryluck, L. (2004). People at the end of life are a vulnerable research population. *Clinical Oncology, 16,* 225-226.

Higginson, I. J. (2005). End-of-life care: Lessons from other Nations. *Journal of Palliative Medicine, 8,* (S-1), 161-173.

Holt, L. L. (2001). End-of-life customs among immigrants from Eritrea. *Journal of Transcultural Nursing, 12,* 146-154.

Hotson, K. E., Macdonald, S. M., & Martin, B. D. (2004). Understanding death and dying in select first nations communities in northern Manitoba: Issues of culture and remote service delivery in palliative care. *International Journal of Circumpolar Health, 63*, 25-38.

Jenkins, C., Lapelle, N., Zapka, J. G., & Kurent, J. E. (2005). End-of-life care and African Americans: Voices from the community. *Journal of Palliative Medicine, 8*, (S-1), 585-592.

John, P. (2000). Elders spoke and young people listened. In A. Fienup-Riordan (Ed). (2005). *Wise words of the Yup'ik Eskimo people: We talk because we love you.* Lincoln: University of Nebraska Press.

John, P. (1991). Introduction. In A. Fienup-Riordan (Ed.). (2007). *Yuungnaqpiallerput: The way we genuinely live.* Seattle: University of Washington Press.

Kaufman, S. R., & Morgan, L. M. (2005). The anthropology of the beginnings and ends of life. *Annual Review of Anthropology, 34,* 317-314.

Kawagley, A. O. (2006). *A Yupiaq worldview: A pathway to ecology and spirit.* Illinois: Waveland.

Kitzes, J. & Berger, L. (2004). End-of-life issues for American Indians/Alaska Natives: Insights from one Indian health service area. *Journal of Palliative Medicine, 7,* 830-838.

Kübler-Ross, E. (1969). *On death and dying: What the dying have to teach doctors, nurses, clergy, and their own families.* New York: MacMillan.

Kuhl, D. (2010). What people want at the end of life. *Journal of the Canadian Medical Association, 182,* 1707.

LeBlanc, T. W., Wheeler, J. L., Abernethy, A. P. (2010). Research in end-of-life settings: An ethical inquiry. *Journal of Pain and Care Pharmacotherapy, 24,* 244-250.

Leininger, M. (1990). Ethnomethods: The philosophic and epistemic bases to explicate transcultural nursing knowledge. *Journal of Transcultural Nursing, 1,* 40-51.

Leininger, M. (2002). Culture care assessments for congruent competency. In M. Leininger & M.R. McFarland (Eds.). *Transcultural nursing: Concepts, theories, research & practice* (3rd ed.). (pp.117-145). U.S.A.: McGraw-Hill.

Leininger, M. (2006a). Culture care diversity and universality theory and evolution of the ethnonursing method. In M. Leininger & M.R. McFarland (Eds.), *Culture care diversity and universality: A worldwide theory of nursing* (2nd ed.). (pp.1-39). Sudbury: Jones and Bartlett.

Leininger, M. (2006b). Ethnonursing research method and enablers. In M. Leininger & M.R. McFarland (Eds.), *Culture care diversity and universality: A worldwide theory of nursing* (2nd ed.) (pp. 43-82). NY: Jones & Bartlett.

Leininger, M. (2006c). Selected culture care findings of diverse cultures using culture care theory and Ethnomethods [Revised Reprint]. In M. Leininger & M.R. McFarland (Eds.), *Culture care diversity and universality: A worldwide theory of nursing* (2nd ed.) (pp. 281-305). NY: Jones & Bartlett.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry.* Beverly Hills: Sage.

Locke, D. C. (1992). *Increasing multicultural understanding: A comprehensive model.* Newbury Park: Sage.

Luna, L. J. (1989). Care and cultural context of Lebanese Muslims in an urban U.S. community: An ethnographic and ethnonursing study conceptualized within

Leininger's theory. (Unpublished doctoral dissertation). Wayne State University, Detroit, Michigan.

Lynn, J. (2005). Living long in fragile health: The new demographics shape end of life care. *Hastings Center Report,* 35, 14-18

Maddalena, V. (2009). Cultural competence and holistic practice: Implications for nursing education, practice, and research. *Holistic Nursing Practice, 23, 153-157.*

McGrath, P., & Phillips, E. (2008). Aboriginal spiritual perspectives: Research findings relevant to end-of-life care. *Illness, Crisis, and Loss, 16*, 153-171.

McMillan, S. C. (2005). Interventions to facilitate family caregiving at the end of life. *Journal of Palliative Medicine, 8*, (S-1), 132-139.

Mohammed, S. & Peter, E. (2009). Rituals, death, and the moral practice of medical futility. *Nursing Ethics, 16,* 292-302.

Napoleon, H. (1996). *Yuuyaraq: The way of the human being.* Chicago: University of Chicago Press.

National Institute of Health (NIH). National Institutes of Nursing Research. State of Science Conference Statement (2004). Retrieved from http://www.ninr.nih.gov/

Olshansky, S. J. & Ault, A, B, (1986). The fourth stage of the epidemiological transition: The age of delayed degenerative diseases. *Milbank Memorial Fund Quarterly, 64,* 355-391.

Pluralistic . 2011. In *Merriam-Webster.com*. Retrieved from http://www.merriam-webster.com/dictionary/pluralistic.

Porock, D., Pollock, K., & Jurgens, F. (2009). Dying in public: The nature of dying in an acute hospital setting. *Journal of Housing for the Elderly, 23*, 10-18.

Quinn, J. R., Schmitt, M., Baggs, J. G., Norton, S. A., Dombeck, M. T., & Sellers, C. R. (2012). Family members' informal roles in end-of-life decision making in adult intensive care units. *American Journal of Critical Care, 21,* 43-51.

Segal, J. Z. (2000). Contesting death, speaking of dying. *Journal of Medical Humanities, 21,* 29-44.

Seno, V. L. (2010). Being-with dying: Authenticity in end-of-life encounters. *American Journal of Hospice and Palliative Medicine, 27,* 377-386.

Sherry, P. (2004). Health care delivery for Alaska natives: A brief overview. *International Journal of Circumpolar Health, 63,*54-62.

Singelmann, J., & Schafer, M. (2010). Dislocation and depression: Social consequences of Hurricanes Katrina and Rita. *Society and Natural Resources, 23,* 919-934.

Teno, J .M., Clarridge, B. R., Casey, V., Welch, L. C., Wetle, T., Shield, R., & Mor, V. (2004). Family perspectives on end-of-life care at the last place of care. *Journal of the American Medical Association, 291,* 88-92.

Thomas, N. D. (2001). The importance of culture throughout all life and beyond. *Holistic Nursing Practice, 15,* 40-46.

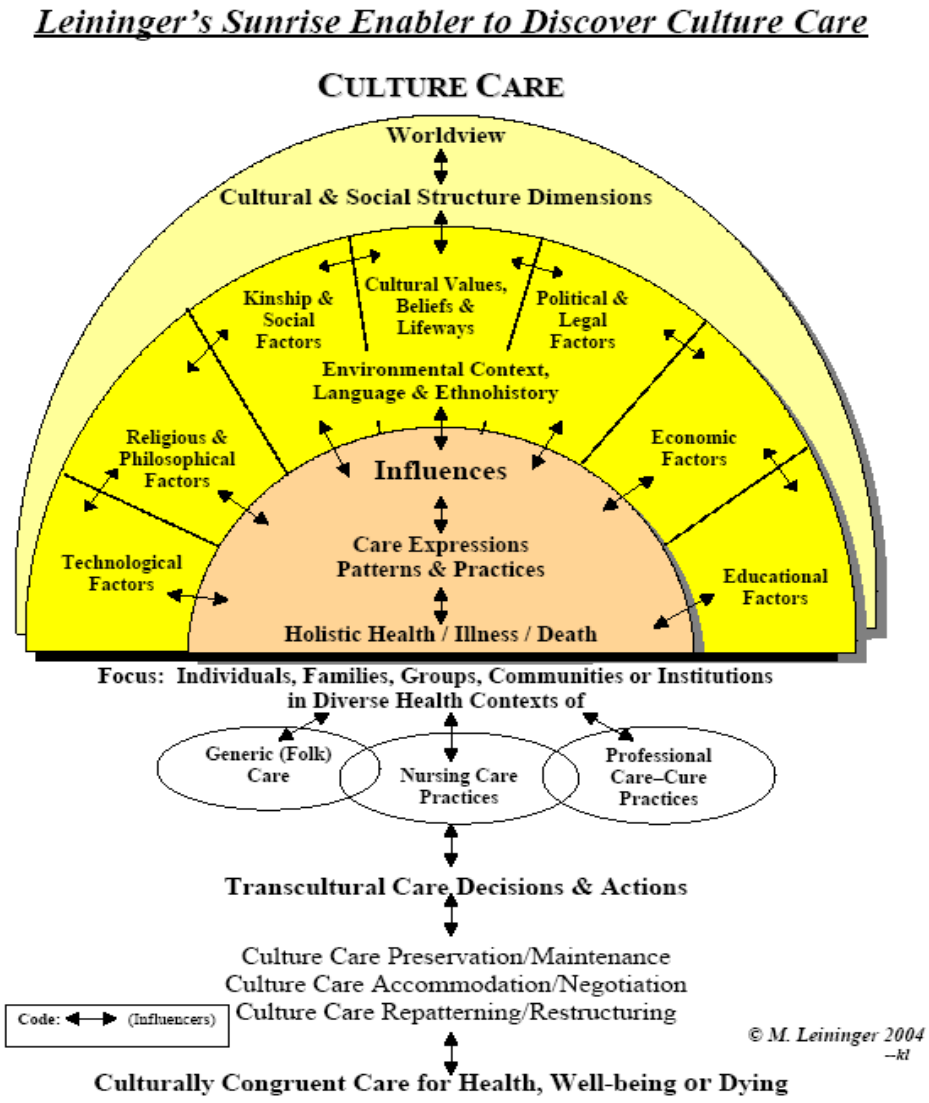
Tulsky, J. A. (2005). Intervention to enhance communication among patients, providers, and families. *Journal of Palliative Medicine, 8*, (S-1), 95-101.

United States Census Bureau. (2012). State and County QuickFacts (2010). Retrieved from http://quickfacts.census.gov/qfd/states/02/0206520.html

Appendices

Appendix A

Sunrise Enabler



Used with Permission by Madeleine Leininger 2010

Appendix B

Stranger to Trusted Friend Enabler

The purpose of this enabler is to facilitate the researcher (or it can be used by a clinician) to move from mainly distrusted stranger to a trusted friend in order to obtain authentic, credible, and dependable data (or establish favorable relationships as a clinician); The user assesses him or herself by reflecting on the indicators as he/she moves from stranger to friend.			
Indicators of Stranger (Largely *etic* or outsider's views) Informant(s) or people are:	Date Noted	Indicators as a Trusted Friend (Largely *emic* or insider's views) Informant(s) or people are:	Date Noted
1. Active to protect self and others. They are "gate keepers" and guard against outside intrusions. Suspicious and questioning.		1. Less active to protect self. More trusting of researchers (their 'gate keeping is down or less'). Less suspicious and less questioning of researcher.	
2. Actively watch and are attentive to what researcher does and says. Limited signs of trusting the researcher or stranger.		2. Less watching the researcher's words and actions. More signs of trusting and accepting a new friend.	
3. Skeptical about the researcher's motives and work. May question how findings will be used by the researcher or stranger.		3. Less questioning of the researcher's motives, work, and behavior. Signs of working with and helping the researcher as a friend.	
4. Reluctant to share cultural secrets and views as private knowledge. Protective of local lifeways, values and beliefs. Dislikes probing by the researcher or stranger.		4. Willing to share cultural secrets and private world information and experiences. Offers most local views, values, and interpretations spontaneously or without probes.	
5. Uncomfortable to become a friend or to confide in stranger. May come late, be absent, and withdraw at times from researcher.		5. Signs of being comfortable and enjoying friends and a sharing relationship. Gives presence, on time, and gives evidence of being a 'genuine friend.'	
6. Tends to offer inaccurate data. Modifies 'truths' to protect self, family, community, and cultural lifeways. *Emic* values, beliefs, and practices are not shared spontaneously.		6. Wants research 'truths' to be accurate regarding beliefs, people, values, and lifeways. Explains and interprets *emic* ideas so researcher has accurate data.	

Appendix C

Observation-Participation-Reflection Enabler

Phases 1 → 2 → 3 → 4			
Focus			
Primary *Observation and Active Listening* (no active participation)	Primary *Observation* with limited participation	Primary *Participation* with continued observations	Primary *Reflection and Reconfirmation* of findings with informants

Used with Permission by Madeleine Leininger 2010

Appendix D

Open Inquiry Guide Enabler

End-of-Life Culture Care Expressions, Meanings, Patterns, and Practices among Yup'ik Eskimo

I. Introduction

The purpose of this study is to learn, through interviews and observations, the culture care expressions, meanings, patterns, and practices related to end-of-life care among Yup'ik Eskimo so that nursing care can be planned and improved.

II. Ethnodemographics

Name:	Informant # (to be assigned by the researcher)
Spiritual Background:	Cultural Background/Ethnic Orientation:
Gender:	Age:
Place of Residence:	Previous Place of Residence:
Language(s) Spoken:	Source of Water:
Source of Toileting Facility:	Source of Cooking or Heating Fuel:
Do you have electricity in the home?	Do you have a telephone?
Do you have a radio and/or television?	Have you been to school? What grade did you complete?
Date(s) of Interview(s):	

III. Cultural Values, Beliefs, and Lifeways:

1. Tell me your cultural story – your tribe and your people.

2. What specific values or beliefs do you possess that you feel identify you as Yup'ik Eskimo?

IV. Kinship and Social Factors

1. Tell me about the Yup'ik Eskimo community.

V. Religious/Philosophical Factors

1. Tell me about the Yup'ik Eskimo practices relate to end-of-life and after death.

VI. Health and Well-Being

Tell me how the Yup'ik Eskimo views health and well-being.

VII. End-of-Life

Tell me what end-of-life or dying means for Yup'ik Eskimo.

VIII. Generic/Family/Folk Care

Tell me what end-of-life care means for Yup'ik Eskimo.
What is good or caring end-of-life care?
What is not good or non-caring end-of-life care?

IX. Professional Care

What can you tell me about your experiences with professional care – care with a healthcare provider.
What can you tell me about your experiences with village healers or traditional healers?

XI. Environmental Factors

Tell me about your environment and how it relates to end-of-life for Yup'ik Eskimo?

XII. Economic, Political & Legal, Educational Factors

Tell me about subsistence and survival for Yup'ik Eskimo.

XIII. Technological Factors

Tell me how technology affects end-of-life for Yup'ik Eskimo.

XIV. Summary Question

What else you would like to share with me about your cultural expressions, meanings, patterns, or practices at the end-of-life?

Adapted from Leininger's Suggested Inquiry Guide for use with the Sunrise Model to Assess Culture Care and Health. Leininger, M. (2002). Culture care assessments for Congruent competency practices. In M. Leininger & M. R. McFarland (Eds.), *Transcultural nursing: Concepts, theories, research & practice* (3rd ed.) (pp. 117-143). U.S.A.: McGraw-Hill.

Appendix E

University of Tennessee Institutional Review Board Form B

FORM B
IRB # 8679-B

THE UNIVERSITY OF TENNESSEE

Application for Review of Research Involving Human Subjects

I. IDENTIFICATION OF PROJECT

1. **Principal Investigator Co-Principal Investigator:**

   Pam Embler
   981 North Trunk Road
   Palmer, Alaska 99645
   (907)775-3428
   pamembler@yahoo.com

   Faculty Advisor:

   Dr. Mary Gunther - Dissertation chair
   The University of Tennessee
   College of Nursing
   1200 Volunteer Boulevard
   Knoxville, TN 37996-4180
   mgunther@utk.edu
   865-974-7589

   Department: **College of Nursing**

2. **Project Classification:** **Dissertation**

3. **Title of Project:**
   End-of-Life Culture Care Expressions, Meanings, Patterns, and Practices among Yup'ik Eskimo

4. **Starting Date:** **Upon IRB Approval**

5. **Estimated Completion Date: 2012**

6. **External Funding** *(if any):*
   - **Grant/Contract Submission Deadline: August 1, 2011**
   - **Funding Agency: Alaska Nurses Foundation**
   - **Sponsor ID Number *(if known)*: N/A**
   - **UT Proposal Number *(if known):*** *Not known at this time*

- **Grant/Contract Submission Deadline: October 15, 2011**
- **Funding Agency: Transcultural Nursing Society**
- **Sponsor ID Number *(if known)*: N/A**
- **UT Proposal Number *(if known):*** *Not known at this time*

- **Grant/Contract Submission Deadline: October 15, 2011**
- **Funding Agency: University of Alaska Anchorage Faculty Development Fund**
- **Sponsor ID Number *(if known)*: N/A**
- **UT Proposal Number *(if known):*** *Not known at this time*

II. PROJECT OBJECTIVES

The purpose of this study is to discover the culture care expressions, meanings, patterns, and practices related to end-of-life among Yup'ik Eskimo.
The goal of this study is to discover emic (generic/folk) and etic (professional nursing) care that promotes culturally congruent end-of-life care for Yup'ik Eskimo.

The research questions are:
1. What are the culture care expressions, meanings, patterns, and practices related to end-of-life care among Yup'ik Eskimo?
2. In what ways do worldview, social structure factors, i.e. "religion (spiritual);kinship (social ties); legal; education; economics; technology; political; philosophy of life; and cultural beliefs and values with gender and class differences" (Leininger, 2006a, p. 14), ethnohistorical, and environmental factors influence end-of-life culture care expressions, meanings, patterns, and practices for Yup'ik Eskimo?
3. In what ways does generic and professional care assist with or inhibit the end-of-life culture care expressions, meanings, patterns, and practices for Yup'ik Eskimo?
4. Based upon the discovery of Yup'ik Eskimo end-of-life care what nursing action/decision modes promote culturally congruent end-of life care expressions, patterns, and practices for Yup'ik Eskimo?

The inclusion of culture at end-of-life has multiple benefits to nursing practice and research. While quantitative, qualitative, and mixed methods research designs are all quite capable of advancing nursing knowledge of culturally situated end-of-life care, I strongly argue that people from diverse cultures can experience end-of-life care differently. I propose a logical first step is discovery. Nurses have a responsibility to promote culturally congruent end-of-life care, this can only occur when end-of-life culture care is known.

The need for research related to end of life care is a National Institutes of Health (NIH)/National Institutes of Nursing Research (NINR) research priority. In the most recent NIH/NINR statement (2004) end-of-life care research specifically end-of-life care transitions is an emerging construct in need of clarification. The discoveries of end-of-life culture care expressions, meanings, patterns, and practices which will lead to improved culturally congruent end-of-life care support the NIH/NINR research recommendations. The inclusion of culture at end-of-life has multiple benefits to nursing practice and research. Quantitative, qualitative, and mixed methods research designs are all quite capable of advancing nursing knowledge of end-of-life culture care. I strongly argue that people from diverse cultures can experience end-of-life care differently. I propose a logical first step is discovery. I have chosen a qualitative ethnonursing

methodology to direct this study. Ethnonursing (Leininger, 2006) differs from ethnography in one main way. Ethnonursing methodology adds the etic (outsider) view to the emic (insider) view of known cultural lifeways. In this study, etic views are nursing views and emic views at the Yup'ik Eskimo views. The goal of ethnonursing is, through the use of action/decision modes (discussed in detail later), to utilize discovered lifeways to promote culturally congruent care; care that is meaningful and beneficial to its recipients. There are approximately eleven Alaska Native tribes within five different geographic regions of Alaska, each with unique linguistic, social, and clan variations (Alaska Native Heritage Center Museum, 2008). Each tribe deserves a full and fair hearing. Ethnonursing method (Leininger, 2006) situates stories to nursing leading to the generation of new nursing knowledge by focusing on culture and care. Discovery will support what is known and add what is unknown about end-of-life care and end-of-life transitions for Yup'ik Eskimo. This study seeks to discover, explore, and understand. Similarities are anticipated however, an assumption of transferability within or between cultures potentiates bias and stereotyping.

The influence of culture on end-of-life transitions is lacking in the research and subsequently poorly understood. I propose that cultural influences add multiple layers and complexities to what is known about end-of-life care. Culturally diverse patient populations challenge health care providers to promote more than culturally sensitive care. Care must be culturally congruent. **In the literature it was determined that research specifically related to end-of-life among Yup'ik Eskimo was markedly under researched.**

References:

Alaska Native Heritage Center Museum. (2008). Culture Map. Alaska's Indigenous People. Retrieved from http://www.alaskanative.net/

Leininger, M. (2006). Culture care diversity and universality theory and evolution of the ethnonursing method. In M. Leininger & M.R. McFarland (Eds.), *Culture care diversity and universality: A worldwide theory of nursing* (2nd ed.). (pp.1-39). Sudbury: Jones and Bartlett.

National Institute of Nursing Research (NINR). NINR Strategic Plan. (2004). Retrieved from http://www.ninr.nih.gov/NR/rdonlyres/9021E5EB-B2BA-47EA-B5DB-1E4DB11B1289/4894/NINR_StrategicPlanWebsite.pdf

III. DESCRIPTION AND SOURCE OF RESEARCH PARTICIPANTS

Purposeful sampling will be used to obtain informants for this study. Participation is voluntary. A gatekeeper will be identified to assist with the identification of potential interested general informants and key informants. The gatekeeper will verbally deliver information about the study, identify appropriate places to display information about the study (see Appendix Study Flyer), and identify appropriate places to conduct talking circles and interviews. Any interested informants, male or female, age 18 and older, who contacts the researcher for further information and consents (See Appendix Study Consent) to participate, is welcome to participate as an informant in the study. Interested informants will be identified in the community setting. The community setting will consist of the Yukon-Kuskokwim Delta, Alaska. The central data collection will be Bethel, Alaska.

*Gatekeeper f*or this study is a trusted Bethel Alaska community member.

Key informants for this proposed study will be males or females, age 18 and older, who self identify as Yup'ik Eskimo, and who are interested in sharing their knowledge of end-of-life transition patterns, beliefs, and practices inherent to their cultural lifeways. The number of key informants will be 12-15 persons.

General informants will be males or females who are age eighteen years old or older, who may or may not self identify as a Yup'ik Eskimo, but who are engaged within the Yup'ik Eskimo culture. These persons may practice with or among or serve the Yup'ik Eskimo community. The general informants will offer

reflective and confirmatory data about the patterns, beliefs, practices of end-of-life transitions among Yup'ik Eskimo. The number of general informants will be 24 to 30 persons.

IV. METHODS AND PROCEDURES

This is a qualitative ethnonursing study directed by the Culture Care Diversity and Universality Theory and the ethnonursing research method.

Purposeful sampling will be used to gather interested informants. The gatekeeper will assist in identification of interested informants (as detailed above), identify the appropriate places to display information about the study and identify appropriate places to conduct talking circles and interviews. A flyer will be used and will be printed in both English and Yup'ik Eskimo.

Data collection will consist of observations, talking circles, and individual interviews. Observations will be recorded in the researcher field notes. Talking circles and interviews will be audio taped and transcribed verbatim.

No observations or interviews will be obtained without prior consent. Consents will be printed in English and Yup'ik Eskimo. In addition consents will be read to participants in English or Yup'ik Eskimo.

A dedicated translator and transcriptionist will be used and will sign a confidentiality statement (See Appendix Confidentiality Agreement) prior to any translation or transcription.

Initially talking circles will be used to gather data. Story telling is central to the Alaska Native culture and talking circles are one way in which knowledge is shared. The rules of the talking circle provide for respectful listening, honesty in speaking, and honor while learning and teaching. In addition, the talking circle honors all points of view. A totem is used to indicate who is speaking and while the totem is in someone's possession all others persons are quiet until the person passes the totem to the next person. No person is required to speak if they do not wish to speak. It is anticipated that talking circles in this study will consist of no more than 8 to 10 individuals. The initial length of time of the talking circle will last no longer than 2 hours. The total number of talking circles will be determined by saturation of the data discovered.

Individuals from the talking circles may be identified and requested for additional interviews. Individual interviews will last no longer that one hour.

Additional talking circles or individual interviews may be needed and will be determined on a case by case basis.

Talking circles and individual interviews will be audio-taped. The researcher will take field notes. All talking circles and informants will be assigned a number. Identifiers and informant numbers will be maintained away from each other. All data, consents, and information used in this study will be maintained in locked cabinets in the researcher's office. All computer held information will be password secured.

All audio tapes and interviews will be transcribed verbatim as described above.

All observations, field notes, audio-taped interviews and talking circles will be analyzed using the four phases of ethnonursing analysis for qualitative data. In the first phase data analysis begins immediately and is continuous throughout the study. The purpose of the first phase is for the researcher to immerse into the community and to identify initial meanings and interpret observations. The emic foci of the domain of inquiry and the research questions are dominant in the first phase. Attention is focused on emerging etic foci related to the domain of inquiry and the research questions. Data during the first phase will be transcribed into a word document by the researcher and expert mentors and initial data coding will begin using NVivo 9 QRS software.

In the second phase similarities and differences will be identified. Meanings will be explored from recurrent components. Saturation of the data and the identification of patterns or meanings situated within the context of end-of-life transitions is the focus of the third phase. The fourth phase of data analyses involves the synthesis and interpretation of the data. The focus is on the abstraction and confirmation of the major themes related to end-of-life transition among Yup'ik Eskimo in community

settings. To ensure the establishment of an audit trail and to satisfy the criteria of the qualitative ethnonursing method all data will be referable back to the raw data, as data collection and analysis occur concurrently.
If persons withdraw from the study all information, related interviews, interview content, and observations will be destroyed.
All audio tapes, observation field notes, transcribed talking circles, transcribed interviews, consents, and demographic information will be held in Dr. Mary Gunther's locked office in a locked file cabinet and on a password protected computer after the completion of the study for three years. At the end of the required post research holding period all study information as noted above will be shredded or incinerated.

V. SPECIFIC RISKS AND PROTECTION MEASURES

Risks inherent to participation in this study are deemed minimal. Participation is voluntary. Informants will not be paid to participate and they will not be penalized in any way for not participating. Informants will receive a small gift of appreciation for participating. Informants may see the questions before deciding to participate. If at any time during the interview informants feel uncomfortable or anxious they may stop the interview for a period of time and then resume or withdraw from the study completely without any repercussions. In this study participants may run in to people that they know in the talking circle, participants will be provided the opportunity to withdraw since their identity cannot be kept completely confidential. Informants will be instructed to not say anything in a talking circle that they do not want others to know.
Informant name and information given will remain strictly confidential. Informants will not be identified by name in any audio tapes, transcriptions, or final study report. Informants will be assigned a number for identification purposes. Informant consent form will be kept separate from all other study information. Informant responses will be kept in a locked cabinet in a locked room and on a password protected computer locked in the researcher's office. Informants are entitled to further inquiries regarding this research. Informants are free to withdraw from this research at anytime without penalty or prejudice. Informants' signatures indicate that have received and have carefully read this consent form. If need be, the consent form will be read to them in English or Yup'ik Eskimo.
All audio tapes, observation field notes, transcribed talking circles, transcribed interviews, consents, and demographic information will be held in Dr. Mary Gunther's locked office in a locked file cabinet and on a password protected computer after the completion of the study for three years. At the end of the required post research holding period all study information as noted above will be shredded or incinerated.

VI. BENEFITS

The interview process may offer informants the opportunity to express concerns or issues that had not been discussed or considered Exploration of how informants feel may benefit them by having the opportunity to express experiences thus helping them feel heard. Information may help future patients and nurses understand end-of-life for Yup'ik Eskimo.

VII. METHODS FOR OBTAINING "INFORMED CONSENT" FROM PARTICIPANTS

Study purpose, risk, benefits, and informant participation will be verbally explained to the informant's satisfaction. The consent form will be read to the informant. Informant understanding and willingness to participate is demonstrated by the signed consent form. Consents will be read in English and Yup'ik Eskimo if necessary.

VIII. QUALIFICATIONS OF THE INVESTIGATOR(S) TO CONDUCT RESEARCH

I am a registered nurse, hold a Masters Degree, and a post master's certification in Transcultural Nursing which is advanced education of the research method and theory, I am a PhD student. I have collaborated with expert mentors and I have obtained interest from key stakeholders in the Alaska Native community.
Dissertation Committee –
UTK College of Nursing
Chair – Mary Gunther, PhD, RN Expertise: Empathy, qualitative research methods.
Sandra Mixer, PhD, RN, CTN-A Expertise: Transcultural Nursing, ethnonursing research method.
JoAnne Hall, PhD, RN Expertise: Marginalized persons and groups, qualitative research methods.
External Members
UTK Department of Anthropology
Gregory Button, PhD Expertise: Anthropological theory, ethnographic research methods, and the dynamics of social change.
Duquesne University College of Nursing
Rick Zoucha, PhD, PMHCNS-BC, CTN Expertise: Transcultural Nursing, ethnonursing research method.

Expert mentors –
Sandra Mixer, PhD, RN, CTN-A
Assistant Professor Nursing-University of Tennessee Knoxville, TN
PhD University of Northern Colorado 2008
MSN University of Texas at Arlington 1996
BSN Saginaw Valley State University 1987
RN Diploma Mercy Central Nursing School 1980
Additional relevant certifications –
Certified trainer for End-of-Life Nursing Education Curriculum (ELNEC)
Certified Transcultural Nurse-Advanced
Rick Zoucha, PhD, PMHCNS-BC, CTN
Associate Professor Nursing-Duquesne University Pittsburgh, PA.
Certificate Forensic Science and Law Duquesne University 2003
DNSc Rush University College of Nursing 1997, changed to PhD 2007)
MSN Texas Women's University 1987
BSN University of the Incarnate Word 1984
AAS Southern Illinois University-Carbondale-Nursing 1982
LVN/LPN Saint Joseph Hospital School of Vocational Nursing 1980
Additional relevant certifications –
Certified Transcultural Nurse

IX. FACILITIES AND EQUIPMENT TO BE USED IN THE RESEARCH

This study will be conducted in the Yukon-Kuskokwim Delta, Alaska. Talking circles and individual interviews will be conducted at a mutually agreed upon private community location by the researcher and the informants. A tape recorder will be used to audio-tape talking circles and individual interviews. A notebook will be used to record field notes. Audio-taped interviews will be transcribed into a word document. An independent transcriptionist will be employed to transcribe audio-taped talking circles and interviews. The transcriptionist will sign a confidentiality agreement. A dedicated translator will be used. The translator will sign a confidentiality agreement.

X. RESPONSIBILITY OF THE PRINCIPAL/CO-PRINCIPAL INVESTIGATOR(S)

The following information must be entered verbatim into this section:

By compliance with the policies established by the Institutional Review Board of The University of Tennessee the principal investigator(s) subscribe to the principles stated in "The Belmont Report" and standards of professional ethics in all research, development, and related activities involving human subjects under the auspices of The University of Tennessee. The principal investigator(s) further agree that:

1. **Approval will be obtained from the Institutional Review Board prior to instituting any change in this research project.**

2. **Development of any unexpected risks will be immediately reported to Research Compliance Services.**

3. **An annual review and progress report (Form R) will be completed and submitted when requested by the Institutional Review Board.**

4. **Signed informed consent documents will be kept for the duration of the project and for at least three years thereafter at a location approved by the Institutional Review Board.**

XI. SIGNATURES

ALL SIGNATURES MUST BE ORIGINAL. The Principal Investigator should keep the original copy of the Form B and submit a copy with original signatures for review. Type the name of each individual above the appropriate signature line. Add signature lines for all Co-Principal Investigators, collaborating and student investigators, faculty advisor(s), department head of the Principal Investigator, and the Chair of the Departmental Review Committee. The following information should be typed verbatim, with added categories where needed:

Principal Investigator: _____

Signature: _____ Date: _____

Co-Principal Investigator: _____

Signature: _____ Date: _____

Student Advisor (if any): _____

Signature: _____ Date: _____

XII. DEPARTMENT REVIEW AND APPROVAL

The application described above has been reviewed by the IRB departmental review committee and has been approved. The DRC further recommends that this application be reviewed as:

[ ] Expedited Review -- Category(s): _____

OR

[ ] Full IRB Review

Chair, DRC: _____

Signature: _____ Date: _____

Department Head: _____

Signature: _____ Date: _____

Protocol sent to Research Compliance Services for final approval on (Date) : _____

Approved:
Research Compliance Services
Office of Research
1534 White Avenue

Signature: _____ Date: _____

For additional information on Form B, contact the Office of Research Compliance Officer or by phone at (865) 974-3466.

Appendix F

Informed Consent

End-of-Life Culture Care Expressions, Meanings, Patterns, and Practices among Yup'ik Eskimo

INTRODUCTION

Thank you for expressing interest in participating in this research study. The purpose of this study is to discover what end-of-life means to Yup'ik Eskimo. I hope that this study will help nurses and other health care providers to understand end-of-life care practices for Yup'ik Eskimo.

INFORMATION ABOUT PARTICIPANTS' INVOLVEMENT IN THE STUDY

The study requires participation in an individual interview that will last no longer than 1 hour. Additional interviews might be necessary. Additional interviews will last no longer than 1 hour.

I will protect your identity in several ways. First I will assign you a number. Your name and your number will be kept in separate locked file cabinets in my office. I will make every effort to maintain your privacy. I will not identify you by name in any reports.
I will be observing and I will record my observations as notes. Individual interviews will be audio taped if acceptable. I will not use any names in the notes or in the interviews. I will have the audio tapes transcribed into a written document. Should names be used in the audio tapes I will not transcribe the name to the written document.
If you change your mind and do not want to be in the study you can leave at any time. All information you have given up until that point will be destroyed. Nothing will happen to you if you do not want to be in the study.

RISKS

Talking about end-of-life may raise concerns or issues that you have not discussed or considered. You may see the questions before deciding to participate. If at any time during the interview you feel uncomfortable or anxious you may withdraw consent immediately and the interview will be stopped. If I sense that you are uncomfortable or anxious I may stop the interview and ask if you want to continue.

_____ Participants Initials

BENEFITS
Talking about your experiences might make you feel heard. The findings of this study may not benefit you directly. Information may help future patients, nurses, and other healthcare providers to understand end-of-life for Yup'ik Eskimo.

CONFIDENTIALITY
All information in this study will be kept private and locked in a cabinet in my office. Nothing with your name will be kept with any of the audio tapes, notes, or written reports. The information will only be seen by me and those people who are helping me. At the end of the study all the materials from this study will be destroyed.

COMPENSATION
You will not be paid to be in this study. It will not cost anything to participate in this study. You will be provided a small gift of appreciation for participating in the study at the beginning of the study.

EMERGENCY MEDICAL TREATMENT
The University of Tennessee does not "automatically" reimburse subjects for medical claims or other compensation. If physical injury is suffered in the course of research, or for more information, please notify the investigator in charge, Pam Embler at (907) 775-3428.

CONTACT INFORMATION
If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study,) you may contact –

Primary researcher
Pam Embler
3795 Providence Drive HSB 312
Anchorage, Alaska 99645
(907) 786 – 4509

Advisor
Mary Gunther
1200 Volunteer Boulevard
Knoxville, TN 37996
(865) 974-7589

If you have questions about your rights as a participant, contact the Office of Research
Brenda Lawson
Compliance Officer and IRB Administrator
UT Knoxville Office of Research
1534 White Avenue
Knoxville, TN 37996-1529
(865) 974-7697 office
(865)974-7400 fax
blawson@utk.edu

_____ Participants Initials

PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at anytime without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed you data will be returned to you or destroyed.

WRITTEN CONSENT

I have read the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature _____ Date _____

Investigator's signature _____ Date _____

VERBAL CONSENT

The consent was read to me. I agree to participate in this study.

Participant's signature _____ Date _____

Investigator's signature _____ Date _____

Appendix G

Leininger's Phases of Ethnonursing Data Analysis Guide Enabler

Fourth Phase *Major Themes, Research Findings, Theoretical Formulations, and Recommendations*
This is the highest phase of data analysis, syntheses, and interpretations. It requires synthesis of thinking, configuration analysis, interpreting findings, and creative formulation from data of the previous phases. The researcher's task is to abstract and confirm major themes, research findings, recommendations, and sometimes make new theoretical formulations.

Third Phase *Pattern and Contextual Analysis*
Data are scrutinized to discover saturation of ideas and recurrent patterns of similar or different meanings, expressions, structural forms, interpretations, or explanations of data related to the domain of inquiry. Data are also examined to show patterning with respect to meanings-in-context and along with further credibility and confirmation of findings.

Second Phase *Identification and Categorization of Descriptors and Components*
Data are coded and classified as related to the domain or inquiry and sometimes the questions under study. *Emic* or *etic* descriptors are studied within context and for similarities and differences. Recurrent components are studied for their meanings.

First Phase *Collecting, Describing, and Documenting Raw Data (Use of Field Journal and Computer)*
The researcher collects, describes, records, and begins to analyze data related to the purposes, domain of inquiry, or questions under study. This phase includes: recording interview data from *key* and *general* informants; making observations, and having participatory experiences; identifying contextual meanings; making preliminary interpretations; identifying symbols; and recording data related to the DOI or phenomenon under study mainly from an *emic* focus. Attention to *etic* ideas is also recorded. Field data from the condensed and full field journal can be processed directly into the computer and coded, ready for analysis.

Vita

Pamela Jane Embler was born and raised in a small rural community in southeastern Pennsylvania.

Pamela received a diploma in nursing in 1996 from Abington Memorial Hospital School of Nursing. After graduation she embarked on a career in critical care nursing. In 2007 Pamela obtained a bachelor degree in nursing from Florida Hospital College of Health Sciences. Pamela obtained a master's degree in nursing with a major in education from Mansfield University of Pennsylvania in 2009 and a post-masters certification in transcultural nursing from Duquesne University in 2010. Finally, this work fulfills the completion of a doctoral degree in nursing from the University of Tennessee, Knoxville in 2012.